

Youth on the Move Annual report 2021

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
KEMRI	Kenya Medical Research Institute
NECC	National Epilepsy Coordination Committee
NCDs	Non communicable Diseases
NCDAK	Non-Communicable Disease 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 care and the right information on epilepsy. It is even more challenging when a society perceives epilepsy as spiritual or supernatural condition rather than a medical condition. It is worse when the little population with knowledge on the condition lack access to medication due to accessibility, availability and affordability challenges. 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 2021. Achievements for year and follow up plans have been presented in this report.

It is estimated that 1,000,000 Kenyans have epilepsy, however only 30% make use of effective treatment. The main reason for this is that the condition 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 various ways to improve this challenging situation. In the year 2008 Kenyan youth with epilepsy initiated Youth on the Move in Nairobi a platform 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 throughout the country and also 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 COVID-19 pandemic put our initiatives under immense pressure this year as we faced a decline in funding from our donors and well-wishers as well as from our income generating venture (internet café). Despite this we worked innovatively with the little support to ensure that we still undertook all our activities without compromising on quality by effectively providing services to smaller numbers and combining some of the activities to cut down on costs. That is why we are grateful for the support of various sponsors including Stitching YotM in the Netherlands for the support they have given this year.

YotM updates the NGO-Board and its sponsors with regular reports, as well as certified audited financial report.

For further questions and/or remarks, feel free to contact us. Both the employees and board members, are happy to share information with you about how we perform our services with the available resources (reachable through phone and email).

With kind regards,



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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%



Epilepsy Awareness in school

treatment gap in Kenya due to lack of facts on the condition and confusion of epilepsy with social cultural myths and misconceptions like witchcraft and demon possession. 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.

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 am lost, and I wish to join and pursue this course hoping I will find myself and live again!*"

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 organisation 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 organisations and County Governments. To reach as follow the link below <https://www.google.co.ke/maps/place/Youth+on+the+Move/@-1.3082051,36.8213851,17z/data=!3m1!4b1!4m5!3m4!1s0x182f10fe4f111d4b:0xa06c3c432b146852!8m2!3d-1.3082051!4d36.8235738?hl=en>



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. In 2021 we employed three strategies for this:

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

For each strategy we explain the activities that we carry out to achieve our goals.

Strategy 1: Empowerment through education, coaching and guidance



YotM educates youth with epilepsy on issues of proper diagnosis and use of anti-epileptic treatment towards management of the condition as one of basic entry points for improved lifestyles. Besides, young people with and without epilepsy are trained as peer educators. Parents/caregivers as well as professional, social, community and welfare workers are equipped with the right knowledge so that they provide the proper guidance to people with epilepsy.

Activity 1.1: Train the Trainer



Movers training ongoing



Trainees sitting for exams

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

Youth on the Move yearly selects a group of 12 marginalized youth (of which six with epilepsy) who are ambitious, but have a low self-esteem and miss the hope for a good future. In one year they are trained as peer educators through classes on epilepsy, culture and identity, team work, youth participation, coaching,

lifestyle and entrepreneurship. Every month, the offered training is closed off with an exam. The youth are also able to practice their skills at the training centre, the Epilepsy Baraka clinic in Mathare, at St. Johns ambulance and also give epilepsy education in religious institutions, non governmental organisations, companies, learning institutions and other clinics and groups.

The future of the young

The youth who follow the course, get an allowance of 450 ksh per day. When they save 50 ksh, they get a bonus of 50 ksh. This means that they have saved around 15,000 ksh 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 how to invest their savings to become financially independent. The Youth receive a certificate upon successful completion of the course.

Result in 2021: 43 young people applied for the training, which allowed us to be very selective in the choice



Photo shows the trainees of 2021 and their guides

of participants in terms of vulnerability, need and interest. The qualified team consisted of a record number of seven different ethnicities, including a Nubian for the first time. The group also had diverse IQ levels. Classes started successfully in February with the training on epilepsy.

The course progressed well through the months alternating between physical and online classes in line with the government directives on COVID-19 preventive measures that included restrictions in physical gatherings. In April, One of Friends of YotM representative from Epilepsy Wellness USA Dr. Catherine Kamau visited the center and trained the Movers on current issues in epilepsy and safety measures for people with epilepsy. Among the trainees was one female with both epilepsy and mild autism who was unable to follow the online classes. As a solution, her brother took the online classes after which he trained his sister. This is a good example of how YotM always thinks in terms of solutions. Out of the 12 trainees 11 successfully completed the course and graduated on 4th December.



Dr. Catharine Kamau of Epilepsy Wellness explaining about epilepsy safety measures at home

Follow-up in 2022: Due to limited funding, in 2022 YotM will select and train 6 young people. 3 with epilepsy and 3 without the condition.

Mover of the Month Award

To motivate active participation of the youth, YotM introduced the Mover of the Month Award, which appears to be very effective. The youth vote monthly for who they think deserves to be the Mover of the Month, while sharing a write up for their arguments on the voting cards. The Mover of the Month receives an award in presence of all youth which contains their picture and a description why the youth had voted for this person. The winner also gets 1,000 ksh. This appears to be a great incentive for youth to perform well, and to make a significant difference for their peers by guiding one another well.

Activity 1.2: Movers Meeting and Movers Picnic



Movers meetings at the movers paradise and online meetings

Objective:

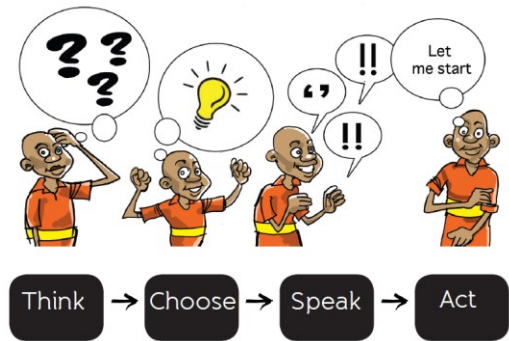
1. Young people with epilepsy develop self-confidence to participate in a group
2. Young people with epilepsy obtain information about their most important themes (such as HIV/AIDS, self-confidence, relationships, abortion, etc.)
3. Young people with epilepsy develop their opinion and dare to share it, even if they do not agree with the majority

Every Saturday (except for the last Saturday of the month) YotM organizes the Movers Meeting at the Training Centre (Movers Paradise). For this meeting, the Youth Coordinators in Training prepare the agenda, chair the meeting and write the minutes under guidance of the Youth Trainers. During the meeting the



Sikika meeting ongoing

Movers evaluate the last held actions and plan for the upcoming ones. After discussing the Movers Actions, they hold the Sikika Talk (Sikika means 'being heard' or 'getting attention' in Swahili). Here the youth with epilepsy are encouraged to discuss about the issues which concerns them. This is not only epilepsy, but also trending topics that affect their lives like further education, politics, economy and how to achieve their dreams in life. With the help of this activity they learn to develop their own opinion, to discuss in a team and how to make wise decisions in life.



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 photo is put in the list of the Mover of the Month.

Movers Picnic



Youth in action during one of the picnics. The game above is who will reach first and pick items at the centre. Whoever picks first wins!

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.

Every last Saturday of the month, Youth on the Move scheduled the Movers Picnic in the Arboretum Park in Nairobi. The activities were 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 received Ksh 1,500 (€

10) to buy snacks and drinks for the team. In doing so, they also learnt to distribute tasks and to deal responsibly with their contribution.

Results in 2021: Movers meetings were a great success alternating between physical and online meetings in line with government regulations regarding COVID- 19 spread. The youth actively searched for information on the chosen topic of discussion before the start of the meeting. This made the discussions more lively, enthusiastic and educative. It was quite encouraging to see the females of 2021 more lively and active right from the beginning of the year. The passionate Social Media Manager Leonard Beckham guided the many online discussions in which the Movers challenged each other with questions. Notable in team of 2021 was punctuality and support for one another. Youth of previous years also joined in the Movers meetings and the picnics where they played together, shared their experiences while providing psycho –social support to the 2021 trainees.

Follow up in 2022: To train more youth who have applied and continue to apply for this training. This activity is very essential and will remain a priority in 2022 as it helps young people to develop and improve their social skills and increases knowledge on different topics. Movers from recent years also continue to enthusiastically attend the talks, resulting in a very valuable exchange between the young people.

Activity 1.3: 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

In Kenya there are more epilepsy patients compared to health professional who are to attend to them. This means, therefore, there is little time for the doctor to explain to the patient what epilepsy is and how to adjust to daily activities accordingly. This is the role that YotM trainees (see activity 4.1.1: Train the Trainer) take on in epilepsy clinics under the guidance of a qualified YotM clinic coach. They explain in understandable language what epilepsy is and how one 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.

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 2021: We successfully offered coaching to patients two clinics: Baraka and Kibera. After the restrictions regarding Covid-19, our coach and the trainees continued to offer group as well as one-on-one guidance to the patients. Through the clinic visits YotM was invited to offer epilepsy education in 6 schools, 4 churches and 2 hospitals in Bungoma and Busia Counties in Western Kenya. Besides 5 caregivers, two youth with epilepsy applied for the 2022 training at our Center.

Follow up in 2022: We will continue to coach people with epilepsy and their caregivers at clinics. This provides an opportunity to learn the patients' progress and how they are coping with other uncertainties like Covid-19. This will also enable YotM to share about the other ongoing activities for persons with epilepsy, including the parents meetings and the Movers Meetings and Picnics. The clinics also provide a good forum for the youths coordinators in training 2022 to but into practise the theory they learn at the center.

Activity 1.4: Book club



The trainees in session discussing one of the books during book club. They use the dictionary to understand the hard words

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

Not all youth in training had an opportunity to complete schools due to uncontrolled seizures and related stigma; for those who did complete, in most cases they missed out on lessons due to seizures or during the days they went for doctor's review. Due to this, they often 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 and knowledge.

Result in 2021: 10 books were read and discussed during classes among the youth. The hard words were discussed and checked in the dictionary so that everyone understood the flow of the books. The trainees as well as trained youth of previous years also borrowed books to read at home on their own. Two youth in training; Joseph and Valentine showed a lot of interest and borrowed an extra new book every month. The Movers of the past years also walked in and borrowed books to read at home and returned during the Saturday meetings.

Follow up in 2022: YotM will continue with the book club activity and hope to expand the number of books with the latest popular books at the Centre as many young people have shown great improvement in their communication skills by reading and sharing books.

Activity 1.5: Movers Yoga

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


In November 2011 YotM introduced Movers Yoga in collaboration with Africa Yoga Project, where the youth attend a two hour session per week. 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.



Result in 2021: The yoga sessions on Tuesday and Wednesday started from the first week that the young people started their program, guided by Hellen. The activity has been well embraced by the young people. During the lockdown, the yoga teacher videotaped the classes weekly and shared them via the young people's Whatsapp group and the YotM Facebook page. In this way, the young people in training continued to participate in the yoga classes from home. This also gave the opportunity for the Movers from previous years and other people who follow YotM Facebook to watch the videos and trainings. The physical yoga resumed in June. The group of 2021 recorded 100% attendance of yoga sessions.

I live with my mum and two little brothers in a small room in Kibera. The outside spaces are limited that there are no play spaces. I never imagined even in this small room I could still exercise and feel fresh...Thanks to Yoga skills. I put our small table on my mum's bed, so that I secure space and do my stretches. I also guide my little brothers and they have become fans. Yoga is so fulfilling and relaxing.

- Tobias Mover in Training, 2021



Follow up in 2022: 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 Hellen

Activity 1.6: 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 the

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.

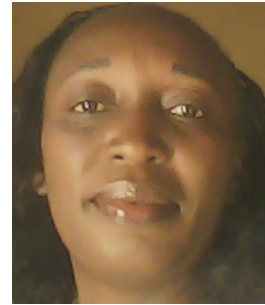
Results in 2021: positive feedback continue to stream in from parents who have benefited from this activity. There is more demand for the parents training as more parents continue to communicate expressing their wish to join in. To manage the demand, 10 parents were put in the formal one year training where they meet once a month at YotM while the other parents formed support groups and meet during the clinic days. This way the clinic coach takes time after the clinic sessions and further educates the parents. The parents' manual is provided to the parents who attend the meetings as at the center, at the clinics as well as to parents who meet with the organization's team individually during the epilepsy awareness.



Parents meeting during one of the Saturdays in 2021

Follow up in 2022: This activity remains important to complement the training of the young people. This is because most participants are the parents trainees of the year. In the upcoming year YotM will provide the Parents Meetings at the Center in Nairobi West, and at the. The Parents' Manuals will be shared with the parents, both to the ones who attend the Parents Meetings and the ones who live too far to attend. Through this manual they can still gain knowledge and read the experiences of other parents on how to encourage their child with epilepsy to live a healthy and independent life.

I have been depressed and confused since 2019 when my daughter Valentine started getting seizures. She had grown up so well, successfully completed her high school, did her sales courses and I had opened for her a business in Eldoret town which she operated with lots of enthusiasm. But hell broke loose on 11th February 2019 when Valentine got her first attack while in her boutique. After the seizure she called me and explained. I passed by in the evening. She was ok and we went home together and shortly before she retired to bed, she got another attack, jerking her whole body. I panicked. I called a neighbour who offered to take her to hospital. She was diagnosed with epilepsy. She has been on medication. This training has helped a lot especially in terms of epilepsy triggers. My daughter too joined the YotM training this year and barely three months, have I seen great change.



Florence – Parent on the Move 2021

Activity 1.7: Movers Cyber & Social Media

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
3. Youth on the Move strengthens its financial independence

Youth on the Move opened an internet cafe in 2008 to offer young people with epilepsy computer lessons and internet. As 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 dexterity for employees.



Photos above shows the youth coach guiding trainees on how to use a computer and internet the building we are located

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 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. The number of followers on Facebook is 7013 with 6928 likes (13 January 2022). According to statistics, we mainly reach the group between 25 and 34 years with this and men are even more active than women.

3: Income generation

The internet café not only offers many opportunities to young people with epilepsy; it is also income generating. We render typing, photocopy, printing, binding, lamination and browsing to our customers at a price. Received income is used partly to pay for fixed costs for Youth on the Move. The Internet café is run by two employees. They provide assistance to young people in training and clients. The financial assistant keeps the administration, and there is also an external auditor who compares income and expenditure every month and keeps us informed of the results.

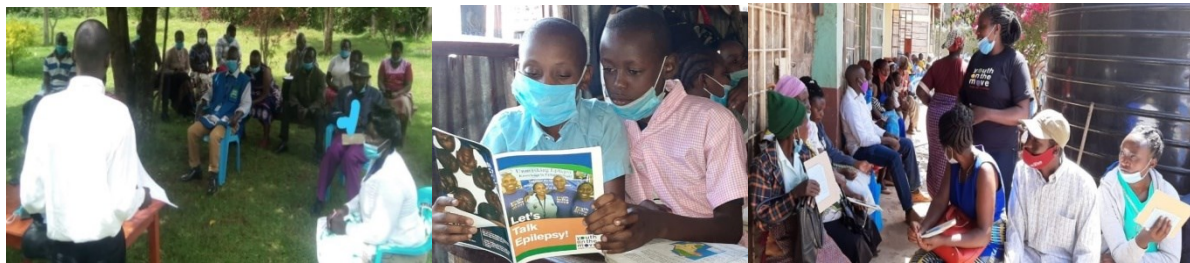
Result in 2021: The Movers continued to improve their computer skills, browsed and communicated with others in faraway places through the offered access to the internet. They also used the internet cafe to do their homework. The former Movers also walked into the café to catch up on current events and share their knowledge with the current Movers in training.

The average monthly income for the year 2021 was € 700. This low income is attributed to effects of COVID-19 since 2019 .The café's performance dropped further drastically in April following the lockdown and record 450 euros. It however picked up again to an average of 650 euros from June. The difficult economic

times in combination with the fear of catching the virus in social places such as in the internet cafe contributed to the decline in income.

Follow up in 2022: The internet café will remain open and we hope that income will recover soon. The internet café will also remain the central meeting point of the previous, current and upcoming Movers. We also continue to use our professional staffs that provide support to both young people and customers at the facilities in the internet cafe.

Activity 1.8: Epilepsy Awareness



Our epilepsy education throughout the country at public venues like schools, youth centres, churches and markets

Objective:

1. Creating awareness and acceptance for epilepsy among 20,000 Kenyans per year by youth in training
2. People learn to understand what epilepsy is and are thus encouraged to provide appropriate support to those with the condition.

Every year, YotM selects various institutions in informal and formal places and in rural areas to give education to groups of people. Their audience learns what epilepsy is, how one can live a good life with it and how one can support a person with a seizure. YotM trains both people with epilepsy as well as the community leaders who can pass over the message to people who have it and to refer them to the right health provider.

Result in 2021: This year YotM created awareness in learning institutions while putting emphasis to groups (CBOs, social workers, youth groups and women groups) . This was in an effort to educate key people who would extend the knowledge to the wider community. The youth in training were very helpful in sharing their personal experiences with the condition during the sessions, which encouraged others to opening up

as well, rather than keeping it a secret. In addition, epilepsy manuals given to each venue trained, in total **10907** people were trained. The social media manager regularly provided information and short videos on various topics related to epilepsy. The Question of the Week on Facebook page prompted a large number of people to discuss important epilepsy issues online.

Follow up in 2022: Despite the active awareness creation of the last years, it was observed that there is still a high demand for more knowledge about epilepsy from the public, YotM is inspired and committed to continue to deliver the trainings to different groups in Kenya and to make creative use of the minimal budget we have to reach more people. This activity remains essential as long as people experience stigma and misunderstanding about the condition especially in this time of covid 19 which has brought lots of confusion in managing epilepsy.



Ongoing epilepsy education in schools at Mukuru kwa Njenga slums Nairobi

Activity 1.9: Train the Community Health Volunteers



Photos of CHVs after and during the training in 2021

Objective: Community Health Workers are well informed about epilepsy and are able to use their knowledge as counsellors for the people with epilepsy in their community.

When organizing the road shows for NECC (see activity 2.1), we found that after our departure we were unable to provide sufficient guidance to the people who had been encouraged by the information to ask for help. That is why YotM developed training for Community Health Volunteers to take up the task in their communities and provide feedback to YotM in terms of people referred to clinics and assisting in bringing those affected and their caregivers to form support groups. Pre and posttest questionnaires are distributed

for the CHVs to respond to. This helps in assessing their level of epilepsy knowledge before and after the trainer in order to set up follow up plans.

During the training, the CHVs are also asked 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 follow up training that gives further insight into epilepsy and how they can guide people who have the condition.

Result in 2021: 50 CHVs in Rift Valley and 50 in Central province were trained and each given an epilepsy manual for future reference as they share the knowledge gained with the communities. 37 patients were guided and refereed for treatments and 11 of the patients reached out to YotM for further guidance. 2 of them who are young applied to join the one year youth training in 2022.

Follow up in 2022: This activity is very central as the CHVs are the link between the patient and the health facilities. YotM's goal is to eventually reach out to all 41 counties in Kenya and contact the CHVs to ensure they follow up in the communities to identify, raise awareness and refer those affected for medical care.

Strategy 2: Lobby & Advocacy

Activity 2.1: 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 2021: The following were the outcomes in 2021

1. Six meetings for the members took place for discussing policy development, education and lobbying.
2. Two Digital media epilepsy education, publication and launch of the NECC/BOA Angaza Kifafa documentary) with 20,000 euros. Epilepsy took place.
3. Three Counties were educated through radio on epilepsy causes and management where Epillose of YotM participated.
4. Four medical seminars took place supported by Novartis Pharmaceuticals



Follow in 2022: 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: Kwale, Muranga, Nakuru and Nandi.

Activity 2.2: Disability Consortium and Non Communicable Disease Alliance of Kenya

Objective: Strengthen cooperation among disability and non-communicable diseases Alliance Stakeholders while empowering persons living with various disabilities.

Youth on the Move strives to partner with many stakeholders as much as possible. This year YotM renewed its membership with the Disability Consortium and the NCDAAK. The aim is to lobby for persons with epilepsy through these bodies as in most cases epilepsy does not receive much recognition and support from both the public and private sector.

Results in 2021: With its mission to empower disability organisations as well as people with the disabilities. The results were as follows

1. Virtual and physical meetings for members were held.

2. 2 Youth with epilepsy invited in NCDAK workshops
3. 2 Empowerment workshops for YotM leader with other organisations leaders help
4. 2 capacity building of disability organisations where members were trained on disability rights and the constitution where Epillose of YotM participated.

Follow up in 2022: More stakeholder engagements to take place so that more young people with epilepsy and disability organizations leaders are empowered.

Activity 2.3: Celebration of international and special days for Epilepsy



Youth with educative epilepsy placards during International epilepsy day walk through the Nairobi Estates

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 and Purple Day for Epilepsy are special days that advocate for greater understanding of epilepsy with the aim of encouraging all governments to provide good epilepsy care. Because St. Valentine was not only a saint of love, but also a patron saint for people with epilepsy, this is also a day on which the young people with epilepsy at YotM ask extra attention for people with epilepsy.



Results in 2021: During St. Valentine day, the youth gathered at YotM Center, discussed at length on the topic of love, they exchanged flowers and shared drinks and snacks in solidarity with those living with the condition. On 8th February, the International Epilepsy day, the youth armed with placards made peaceful demonstrations in Nairobi West Estate where the YotM center is located. It was a door to door campaign in commercial businesses and homes to educate the residence on epilepsy.

On Purple day YotM partnered with other epilepsy stakeholders and lit the tallest building in Nairobi City purple and engaged the media through various platforms on talking about epilepsy and purple day.



UAP towers lit purple during Purple day

Follow-up in 2022: YotM will continue to celebrate these days in the coming years to bring positive attention to people with epilepsy and create more understanding for the condition.

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 NHIF (National Hospital Insurance Fund, a national health insurance fund) aims to ensure that people with a low income can also insure themselves, namely for € 5 per month. However, a large number are unable to pay this amount. In addition, medicines are not always available. Young people regularly indicate that they want epilepsy care to be available and affordable for everyone. They started a petition in August 2009 for available and affordable care.



Joseph received award for collecting signatures for petition

This activity not only stimulates the government to provide better care, but at the same time we achieve two other goals:

1. Young people are encouraged to talk about their own experience with epilepsy, which helps them to overcome their shyness
2. The young people even spend their free time talking to people in crowded public places (such as bus stops) to inform them about epilepsy before asking for their autograph.

Three prizes are awarded each month to young people who have collected the most signatures. The first prize is €10, the second prize is €5 and the third prize is €2 (photo shows Joseph Rabai receiving the prize for collecting the most signatures in August 2021).

Result in 2021: The number of signatures collected were 2,845. This is less than normal due to the corona rules that limited the youth to collect signatures in public. They look forward to the moment when the rules will be abolished again and it will be easier for them to collect signatures again. The plan is to hand over these signatures to the umbrella body NCDAK designated to petition the Ministry of Health.

Follow-up in 2022: We see the need to continue our petition to push governments to make epilepsy care affordable, available and accessible to all, especially during this Covid 19 pandemic that has left so many people unemployed. Continuing the petition process is also a good strategy to continue reaching and informing more people about epilepsy.

Strategy 3: 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.

Activity 3.1: Review of national epilepsy care guidelines

Objective: To keep national epilepsy care guidelines up to date so that doctors can consult them to make the correct diagnosis and prescribe correct medication.



The NECC members at Upper Hill Medical Center during the January 2020 meeting

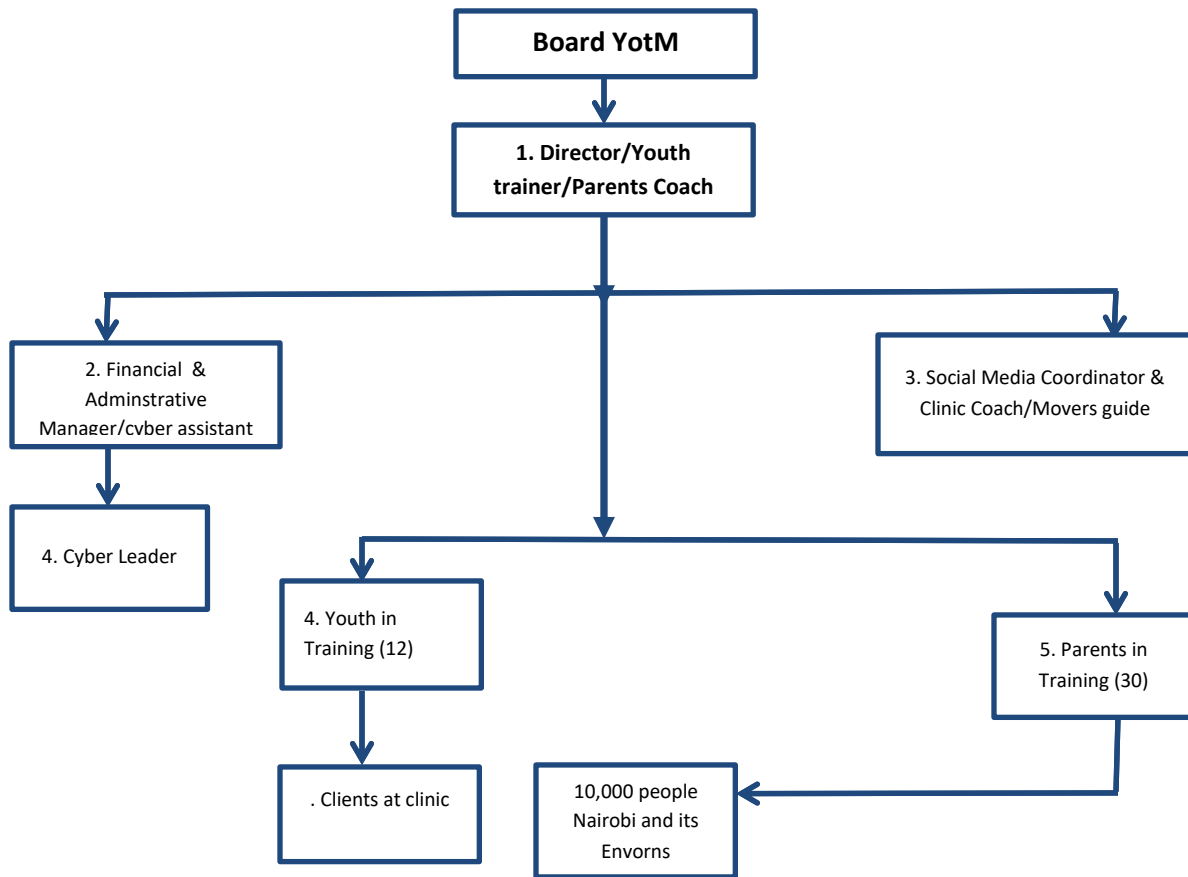
Every other year, the members of the NECC review the content of the Epilepsy Guidelines for the Management of Epilepsy to determine whether changes need to be made due to new insights or changed circumstances. This ensures that healthcare providers have access to reliable information for the healthcare provision for people with epilepsy.

Results in 2021: Selection of a planning committee to refine the guideline, organize printing and distribution

Follow up in 2022: NECC is committed to keeping the guidelines for epilepsy care up to date and disseminating. This ensures that healthcare providers have access to reliable information for the provision of care for people with epilepsy. In NECC AGM, Neurologists presented suggested drafting another guideline for management of epilepsy among children (pediatric epilepsy)

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. Jane Wahome (BSc Business Administration): Financial & administrative Manager/Cyber Assistant
3. Leonard Beckham Ouma: Social Media Assistant/clinic couch and youth guide
4. 12 Youth in Training
5. 30 Parents in Training
6. Haniph Asman: Cyber Leader (Diploma IT)

Appendix 1: Board of Youth on the Move

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

Board of YotM in Kenya:

Sam Kiwinda	Digital Consultant
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

Board of the YotM Foundation in the Netherlands

Josefien de Kwaadsteniet:	Chairman (independent trainer and advisor in international development cooperation, de Kwaadsteniet Training & Co.)
Tom van der Velpen:	Treasurer (interned at YotM in Kenya in 2012) Project employee Under the pans, The Rainbow Group).
Karijn Aussems:	Secretary (previously director at YotM in Kenya, now researcher and teacher at Amsterdam UMC

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

Tuesday Class	Epilepsy	Culture and identity	Coaching	Teamwork	Youth Participation	Lifestyle	Entrepreneurship	Finals
Ake	90	71	81	81	93	92	82	84
Ann	81.5	82	81	81	93	90	86	90
John	81	72	60	72	72	94	73	86
Rabai	68	63	90	75	77	60	71	78
Lucas	60	41	60	65	68	-	-	-
Zaria	62	68	65	70	61	65	60	73

Wednesday Class	Epilepsy	Culture and identity	Coaching	Teamwork	Youth Participation	Lifestyle	Entrepreneurship	Finals
Lambert	84.5	84	80	90	95	91	90	88
Valentine	72.5	73	76	91	84	95	85	90
Naom	71.5	79	93	70	87	95	87	88
Victor	56.5	64	60	68	80	73	75	74
Tobias	63	60	52	60	64	65	61	66
Ayelech	75	84	90	85	77	94	84	92

Appendix 3: Awareness Venues and Numbers Reached

County	Place	Venue	Month	Trainers	Number trained
Narok	Suswa	Enkiloriti primary	January 2021	Eric	441
		Enkiloriti Secondary		Eric	350
		Enooseyia Secondary		Eric	300
		Gospel Church Enooseya		Eric	156
		Ilooioti Primary		Eric	396
		Ilturot Primary		Eric	430
		Kiruk Primary		Eric	387
		Catholic Church Kiruk		Eric	64
		Matonyok Secondary		Eric	189
Nandi	Kapsabet	Nandi Primary		Purity	365
		Namungoi Primary		Purity	397
		Kamombo Primary		Purity	493
		Kapsingak Church		Purity	30
		St. Peters Catholic Church		Purity	173
Kitui	Ikutha	Ikutha Youth Group		Eric	41
		Maluma Secondary		Eric	208
		Simisi Secondary		Eric	246
		Simisi Primary		Eric	308
		Mwaathe Secondary		Eric	195
		AIC Ikutha		Eric	94

		Kalivu SDA Church Group		Eric	121
		Kalawa Gospel Church		Eric	93
		Mwanianga Secondary		Eric	185
		Nzaini Youth Group		Eric	53
Machakos	Matuu	Tei wa Ngai clinic Matuu		Epillose /purity	74
Nairobi	Baraka	German Doctors (Baraka)		Beckam	41
	Kibera	MSF Kibera Clinic		Beckam	09
	Dandora	Dandora Self Help Group		Beckam	35
	Kahawa West	Kahawa West Special Group		Beckam	20
	Kibera	Kibera SDA Youth Group		Beckam	30
Makueni	Mbooni	AIC Kikima	February 2021	Purity	90
		Tei wa Ngoo sya Yesu Children Home Kikima		Purity	106
		Nduluku Independent Church		Purity	54
		Kitundu Secondary staff members		Purity	296
		Kitondo Gospel Church		Purity	89
		Mukimwani Youth Group		Purity	34
Mwingi	Mutomo	Ikanga Youth Group		Eric	19

		Kisayani Children Home		Eric	79
		Kyatune Primary		Eric	207
		Enzau Youth Group		Eric	25
		AIC Kyatune		Eric	100
Transzoia	Kitale	St. Antony Academy		Eric	104
		Kitale Academy		Eric	246
		PAG Church Bikeke		Eric	87
		Nyabomo SDA Church		Eric	92
		Mitoni Mitatu Youth Group		Eric	30
		Mabondeni Academy		Eric	183
		Kabuyefwe Friends Group		Eric	24
Homabay	Ndthiwa	Africa Independent Church of God		Purity	54
		Langoromo Youth Group		Purity	23
		Ruga Youth Group		Purity	48
		St. Camilus Ojunge Group		Purity	26
		Maguti Women Group		Purity	46
		Mbai Innovative Good Workers Group		Purity	29
Nairobi	Mathare	German Doctors (Baraka)		Beckam	39
	Kibera	MSF Kibera		Beckam	14

Machakos	Athi River	Mavoko Youth Group		Eric	45
		Kwa Maria Association		Purity	60
			March 2021		
	Athi River	Athi River Academy		Epillose	235
Nairobi	Dagoretti	Israel Chrch		Beckham	250
Nairobi	Kasarani	Bethalem Orphanage		Epillose	17
Kajado	Kitengela	Noonkopir Youth Group	April	Epillose	34
Nairobi	Langata	Kibra Power Talent Search		Beckham	60
	Dagoreti	KABIRO PRIMARY KAWANGWARE	June	Beckham/Joseph	163
	Dagoreti	KAWANGWARE PRIMARY	July	Beckham/Victor	150
	Dagoreti	JOYSPRING ACADEMY KAWANGWARE	July	Beckham/Victor	70
	Langata	ST. STEPHENS ACADEMY KIBERA	July	Clifford/Naom	120
	Langata	FRIENDS PRIMARY KIBERA	August	Beckham/Clifford	140
	Makadara	Rafiki youth organisation lunga lunga	August	Beckham/Ake	09
Kiambu	Mwihoko	Kiserem foundation mwihoko	August	Beckham/Epillose	15
Nairobi	Kasarani	Thom Rehabilitation	September	Epillose	14
Nairobi	Pumwani	Baraka German Doctors Hospital	September	Beckham/Miriam/Joseph	288
Nairobi	Westlands	Kangemi caregivers forum	October	Beckham/John	22

Machakos	Matuu	Tei Wa Ngai dispensary	October	Epillose	315
Nairobi	Embakasi	G-thamini slums tournament	October	Epillose/Beckham	67
Nairobi	Langata	Ibrahim academy	October	Beckham/Tobias	53
Homabay	Rachuonyo North	Gendia Primary	October	Epillose	350
	Rachuonyo North	Nyaburi Primary	October	Epillose	302
	Rachuonyo North	Hope girls Epilepsy clinic	October	Epillose	60
Total Number of People Reached					10907

TO ALL OUR SPONSORS, WELL WISHERS, PARTNERS, BENEFICIARIES OF OUR ACTIVITIES, BOARD MEMBERS AND STAFF; YOUTH ON THE MOVE SAYS; THANK YOU FOR SUPPORTING OUR CAUSE