

Youth on the Move Report -2019

Empower youth with epilepsy through education, social interaction and entrepreneurship.



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"I used to be at home and I was forbidden to do things on my own. My parents thought if I walk alone I would get an attack. I was not even given a chance to play and have fun. This brought me in an isolated life. But since I joined YotM this year I got to learn about epilepsy and I am more confident to undertake activities and to interact with others. My father joined the Parents Meeting and he is now encouraged to give me my space. Since then I can do most things on my own and I am very excited about it. If there's something I don't know, I feel free to ask people's support, though in the beginning I used to sit on my own and worry in silence. I also used to go home alone, but now I am courageous enough to mingle and to suggest my fellow members to travel together when returning home after classes. I have learned to do my homework on the computer and begin to be more capable to develop myself, make informed decisions and take action."

Christopher Oduor, 29-year-old, Mover in Training, 2019



Introduction

Kenya has in the recent past experienced changes in the health sector. Universal Health care was recently rolled out in four counties. There has been an increased focus on Non-Communicable Diseases given the disease burden. However, epilepsy continues to be missed out as it affects a smaller population than other NCDs. This whereas more than 1,200,000 Kenyans live with epilepsy and approximately 768,000 (64%) of them don't make use of anti-epileptic drugs. Access to effective treatment is expensive for most persons living with epilepsy coupled with ignorance and misconceptions associated with the condition. Beliefs such as epilepsy is witchcraft, demon possession or punishment for wrong doing pushes those affected to seek alternative treatment like spiritual rituals. Due to the ineffective nature of such treatments, persons with epilepsy end up battling mental effects as a result of living with a condition that attracts stigma and rejection. The consequence is a life in social isolation and financial dependency that results in poverty cycle and worse off mental challenges

Fortunately Youth on the Move (YotM) developed strategies to improve this situation. Eleven years ago Kenyan youth with epilepsy initiated Youth on the Move (YotM) to develop opportunities for their future. YotM offers epilepsy trainings, personal coaching, and connects youth with epilepsy with researchers, policy makers and health providers. Together they achieve the best possible approach to control their epilepsy seizures and to create opportunities for a pro-active participation in society through other innovative awareness creation in communities.

The implementation of YotM activities is partly facilitated through the profit of YotM's Movers internet cafe in Nairobi. Bank of Africa Kes. 1,0000,000/= as well as the support of other Dutch donor organisations and individuals.

YotM updates the NGO-Board and its sponsors with regular reports, as well as certified audited financial report. We share a report of the efforts of 2019, the results and how we plan to follow up on our activities in the year 2020.

In case you have any questions or suggestions, do not hesitate to contact us. Our staff and board in Kenya and the Netherlands are pleased to communicate with you to share more information how we implement our services with the available means.

With kind regards,



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1 Relevance of the programme in Kenya



The chance to getting epilepsy is three times higher in Kenya than in the Netherlands and other developed countries like The USA. However, more than 768,000 Kenyans with epilepsy don't make use of anti-epileptic drugs as it is often considered to be a result of witchcraft, demon possession and a punishment of God. This hinders them to fully participate in society, as they are often denied at school, work, in religious institutions and other social gatherings. This makes it even harder for them to utilise their rights and to prevent violence, unprotected sex and unplanned pregnancies. Researchers in Zambia state that 37% of persons with epilepsy has been a victim 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 addition to their medical care. The youth gave us several reasons why they want to contribute in organizing activities:

1. Wanting to improve their welfare and those of others affected in all parts of the country
2. Wanting to reactivate their social lives and live life to the fullest despite having epilepsy
3. Very interested in meeting other people, especially fellow youth with epilepsy
4. Wanting to have someone they could ask about epilepsy

One of the youth said: *"It doesn't not matter what I have been through, my past is gone, my now and my future matters and for this reason this knowledge has come at the right time."*

2 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



3 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 organisations in various counties.



4 Strategies and activities

To improve the lives of persons with epilepsy, YotM united policymakers, researchers, healthcare workers, welfare workers and persons with epilepsy to work as one strong team achieving the mission of controlling epilepsy seizures and creating opportunities for persons with epilepsy to live as productive citizens in society. For this YotM was active in three areas:

1. Research
2. Lobby and Advocacy
3. Policy Development
4. Empowerment of youth with epilepsy through education and guidance

Below we have described per strategy the type of activities we implemented which contributed to the achievement of set objectives.



One of the Youth on the Move staff engaged one of its donors; Bank of Africa staff during Purple Day 2019 in demonstrating first aid and various epilepsy seizures in one of advocacy actions called Angaza Kifafa (shine a light on epilepsy)

4.1 Strategy 1: Research

Objective: To study, document and provide the current insights on the situation for people living with epilepsy in Kenya and the impact of empowerment services offered to them

In the last eleven years Youth on the Move has been able to empower people living with epilepsy, including their care givers, peers, community members, policymakers and health care providers. This has provided the organisation with a lot of insights on their situation. However, this information has

not been studied scientifically and documented and is therefore not available for further use by other professionals in the field. Therefore the organisation will start involving research in their activities with the youth living with epilepsy. For that, the participatory action research (PAR) will be used as the research strategy (Abma et al, 2019).

Results in 2019: Epillose Musimbi started to develop her research proposal for pursuing a PhD and would present this to one of the Kenyan Universities.

Follow up in 2020: in the upcoming year Epillose will study the available academic publications regarding the topic and develop the research plan.

4.2 Strategy 2: Lobby & Advocacy

Activity 4.2.1: NECC (National Epilepsy Coordination Committee)

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



In 2008, when YotM started their services in Kenya, they noticed there was little partnership between the stakeholders in epilepsy care. Therefore they put efforts to form the National Epilepsy Coordination Committee (NECC) in partnership with neurologist Prof. Kioy, the Ministry of Health and various other stakeholders. The committee aims to strengthen the partnership among stakeholders in Kenyan epilepsy care. Under the current chairmanship of Dr. Symon Kariuki and the efforts of YotM's director Epillose Musimbi as secretary, the committee represents policy makers (the Ministry of Health, WHO, ILAE, IBE), researchers, pharmacists, civil society organisations and last but not least persons living with epilepsy. The committee members meet on a bi-monthly basis to develop policies and to organise joint activities for the awareness creation on epilepsy among health providers as well as the community members.

Results in 2019: The committee welcomed three new organisations who registered as members (Kiserem Epilepsy Foundation, Ceska Limited and NFSS Kibra) and actively created awareness with their campaign Angaza Kifafa (Shine a light on epilepsy). The Bank of Africa was once again very satisfied with NECC's awareness creation, and therefore committed themselves to extend their financial support for the national campaign Angaza Kifafa (epilepsy in the limelight) to 2020. NECC successfully organised four roadshows in Embu, Kitui, Kisii and Homabay. With the support of the County government of Embu and Medicines Sans Frontiers (MSF) NECC also conducted a one day epilepsy medical seminar to 35 health workers in Embu county. Another medical seminar supported by the health department of Kisii county was conducted to 27 medical officers held at the Kisii County Teaching and Referral Hospital. Youth on the Move and Association of Neurologists supported the medical seminar to 40 medical officers held at the Homa Bay County Teaching and Referral Hospital. Youth on the Move trained Community Health Volunteers in all the four Counties and made follow ups to ensure the trained CHVs passed the knowledge to their community members.



Follow up in 2020: With the continued spirit and active participation of NECC-members the Bank of Africa has committed to support the campaign in 2020 to reach out to people with epilepsy in Kilifi, Kiambu, Isiolo and Tharaka Nithi. NECC also continues to encourage pharmaceutical companies and other corporates to financially contribute in conducting medical seminars and CHV-trainings for the medical staff to be well trained on how to offer medical support to people living with epilepsy. The member organisations will also be approached to support the open day activities.

In regard to leadership of the committee, during the AGM in November 2019, members agreed to elect some officials from other organizations in order to enhance their participation in the Association. Epillose of YotM who had successfully served as the secretary for 5 years stepped down to pave way for Fred of Foundation for People with Epilepsy while the Treasurer Anderson paved way for Judy Kariuki.

Activity 4.2.2: Petition for the government

Objective: Youth have influence in policy development for epilepsy care and have a voice which is heard and taken seriously by policy makers.

The youth regularly state that they wish Epilepsy Care to be offered or at least subsidized so that it is more affordable. To make this come true, they have developed their petition in which they request the government to make Epilepsy Care affordable and available for all. They started to gather signatures in the month August 2009 with the aim to raise a significant number of signatures. We learned that this action meets more than only the main objective:

1. The youth go to crowded public places, such as buses, and educate them about epilepsy and ask for signatures for the petition.
2. The youth are stimulated to speak about epilepsy, this is a form of encouraging them to speak in public and to share their knowledge and experiences

In 2018 the youth delivered 93,377 signatures to the Ministry of Health, Non-Communicable Diseases Department and was again presented during the NCDAK-media briefing in January 2019. The NCDAK (Non-Communicable Disease Alliance in Kenya) suggested that this should be used as an example for all other organizations for people with NCDs. Dr. Kibachio the then head of NCDs Ministry of Health mentioned that each signature showed awareness and concern for people with epilepsy and therefore demanded commitment for epilepsy to be taken as a serious NCD like cancer and hypertension.



Result in 2019: The youth continued to collect signatures to be used to draw more attention among the policymakers to push for better access to care. A total of 4,485 signatures were collected. Not only the youth who were in training but also the former youth actively contributed in collecting signatures and kept their involvement in the movement of Youth on the Move that demands for better access, availability and affordability of epilepsy care.

Follow up in 2020: since we still encounter people with epilepsy who even cannot afford Ksh 500 per month for NHIF-payment (health insurance), we see the need to continue our petition action to keep the government pro-active in making epilepsy care affordable, available and accessible to all. Besides as a strategy to reach out to more people and educate on epilepsy. The organisation plans to partner with Non Communicable Disease Alliance of Kenya (NCDAK) an umbrella body of all organisations focusing on non communicable diseases to present the petitions once again to the cabinet secretary of health during the media briefing in March 2020.

4.3 Strategy 3: Policy Development

Youth on the Move aims for an active collaboration between policy makers, researchers, health providers and clients to improve the lives of youth with epilepsy. YotM networks with stakeholders to involve youth with epilepsy as serious partners in the design of epilepsy care, so that they are better able to respond to their needs and expectations.

Activity 4.3.1: Revising of National Guidelines for Epilepsy Care

Objective: Keeping the National Guidelines for the Management of Epilepsy up to date so that doctors can utilise the insights on epilepsy in their diagnosis of people with the condition.



The NECC-members at Upper Hill Medical Centre during the meeting in May 2019

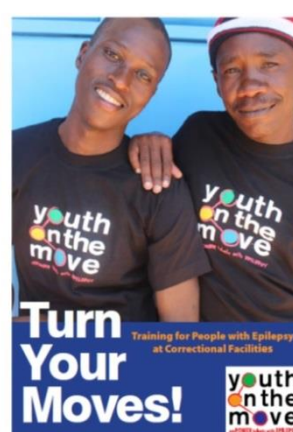
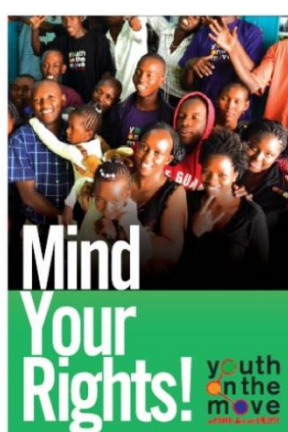
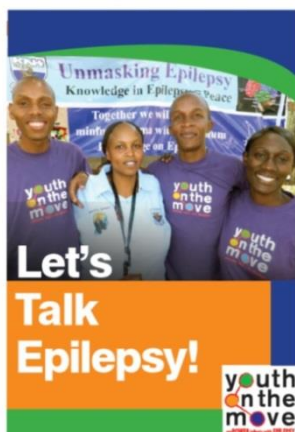
Once every two years the NECC assesses the content of the Epilepsy Guidelines for the Management of Epilepsy to make revisions where necessary to ensure that Kenyan health providers have access to reliable information for the provision of epilepsy care to their clients. The guidelines have played a great role in the treatment of epilepsy. The trained doctors, clinical officers and nurses in the various Counties now make use of the guidelines.

Result in 2019: In April NECC successfully conducted the guidelines review. Professionals from both the private and public sector participated. Afya Research Africa and ANDREF committed to sponsor the printing of the 3rd edition.

Follow up in 2020: At the moment the guidelines are in the process of being approved by the Ministry of Health before being printed and launched during the International epilepsy day in February this year. The guidelines will be provided to the medics that will attend the medical seminars. NECC will further their request to potential sponsors to provide their contribution in printing more guidelines so that it can be shared with the health facilities countrywide to ensure consistency in provision of epilepsy care. Further on, the next revision is planned for 2021.

4.4 Strategy 4: Empowerment through epilepsy education and guidance

For the empowerment of youth with epilepsy, we train youth with and without epilepsy as peer educators, guide their parents and train professionals in social work to have the right knowledge to offer guidance to people with epilepsy.



Activity 4.4.1: Train the Trainer

Objective: In 2019 twelve youth (six with epilepsy and gender balance) are trained as peer educators and developed the skills to offer professional awareness creation and coaching

Youth on the Move yearly selects twelve marginalized youth 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 culture and identity, team work, youth participation, coaching, lifestyle and entrepreneurship. Every month the offered training is closed off with an exam.

The youth practice their skills in our training center, at the Epilepsy Clinics at Baraka Health center in Mathare slums of Nairobi run by German doctors and at MSF clinic in Kibera slums of Nairobi run by AMREF in partnership with the County Government of Nairobi. The youths also give epilepsy education in faith based organizations; learning institutions, support groups for adults and youths, companies, and other clinics.

"I used to doubt if I was able to take care of my child despite having epilepsy. Fortunately my husband found out about YotM. He introduced me to the organisation and their programme has helped me live positively with my condition while taking care of my child well. The Movers Meetings have played a great role in improving my listening and communication skills. I no longer shy away from any topics shared. The opportunity I was given to share my experience with the staff of Bank of Africa during this year's Purple Day made me realize my potential in training and conversation skills. I'm half way the training now and I already feel fully empowered."

- Rosemary Wachira, Mover in Training, 2019

The future of the trainees

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

"Through the training in 2019, I have accepted my condition with epilepsy. It gave me courage to believe that despite epilepsy I can undertake activities and take the responsibility to develop and utilise my talent as a drawing artist. I draw portraits of people and animals. For an individual portrait I charge 1,500 Kenya shillings and knew to sell the first eight in four months."

- Emmanuel Kasina, Mover in Training, 2018.

Results in 2019: 58 youths applied for the training, which enabled YotM to be very selective who to consider for the training. Among the selected team, three were very openhearted from the beginning while nine of them were very shy for the first few months. The team comprised five diverse ethnicities with one being of Ethiopian origin. With the help of the personal guidance and the PDP talks (Personal Development Plan) with the trainer in April (in which they also discussed private challenges), they started to feel free to open up. The youth who were selected for the training were very committed and present during the classes and their internship. Two youths dropped in March as they received scholarships and bursaries to continue their formal education and were replaced by other youth who

had applied in the beginning of the year. In September one of the youth of Muslim background dropped as she had to go back to school. One of the youth living with epilepsy in training was illiterate. The youth did not get a chance to undergo formal education as the parents feared being stigmatized as a whole family and therefore decided to isolate the boy and lock him within the home compound. Besides, the parents did not want the public to know the shame the boy brought to the family. The youth was offered extra guidance and did oral exams instead of written exams. The youth team of this year was very time conscious, social, open minded and freely shared their opinions.

The youth of 2019 broke the record in the history of the organization with their saving culture with the highest saving Kes. 51,000/=. A figure that has never been achieved before. The youth who saved this attributed her secret to walking half the journey to the center and pay less bus ticket in order to save more. She plans to start a hair and beauty salon with the saved cash.



Follow up in 2020: in the upcoming year we offer the training to 12 youth (6 with epilepsy and gender balance) again. The great demand for the training enables us to select youth with high motivation levels. Therefore we also have high expectations of their participation in 2020. This year we will also make an extra training manual for this course that we offer to suit the participating youth with cognitive challenges. We will also follow up on the implementation of oral exams in stead of written exams for those who have challenges in writing in case we have those illetrate applying for the training.

Activity 4.4.2: Epilepsy Education

Objective:

1. Creating awareness and acceptance for epilepsy among 40,000 Kenyans per year
2. People understand what epilepsy is which encourages and enables them to offer the right support to the people who have the condition.

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



Results in 2019: The organisation received extra funding that enabled the youth and staff to

reach out to more people in the awareness creation. Instead of 40,000 people, they targeted 80,000 community members. All requests for epilepsy awareness were attended to. The youth travelled to various places to share the knowledge on the condition. As at end of the year 65,807 people had received education on epilepsy through various institutions and organised groups. The staff and the team therefore sat, discussed and strategised on reaching the remaining 14,547 people in January and February of 2020. Achievement of an early high number of people reached is attributed to the following:

1. Through greater partnerships with various stakeholders like Tei Wa Ngai in Matuu, and Manobis Refugee group in Nairobi who have invited us to training groups including teachers of special needs.
2. The Community Health Volunteers trained by the organisation in various Counties have played a great role in mobilizing groups and inviting the Movers to partner with them to further the education.
3. The current youths have taken up a stronger role in mobilizing groups in their rural areas through their primary and secondary school teachers, village elders and their parents.
4. Prison welfare officers have also played a role in providing refereral to schools from their rural areas for awareness creation.



“In 2017 at my secondary school I used to run away from other pupils if they had a seizure near me, fearing that I would get it if I were close. I even thought I would get epilepsy if I made use of the same latrine. First I had to clean it before I dared to use it. We even wouldn’t eat the groundnuts that they had carried from their homeplace. In my area (Nyakach) people think that a person with epilepsy must rub their back at the place where the donkey has rubbed their back. This would help to cure epilepsy. When I saw the invitation for YotM’s training I applied because I wanted to know more about it. Now I know better what epilepsy is and how one can be assisted. I became the Mover of the Year 2018 and that made me the youth guide for 2019 and

now I assist youth to educate others on epilepsy all over the country. Through these efforts we keep on building our insights, skills and self-esteem.”

Eunice, 20-year-old, Nairobi, Mover of the Year

Follow up in 2020: As we keep on receiving a lot of requests for the awareness creation, we continue availing ourselves to provide the trainings to various groups and institutions. This activity remains essential as long as people experience stigma and misunderstanding regarding the condition.

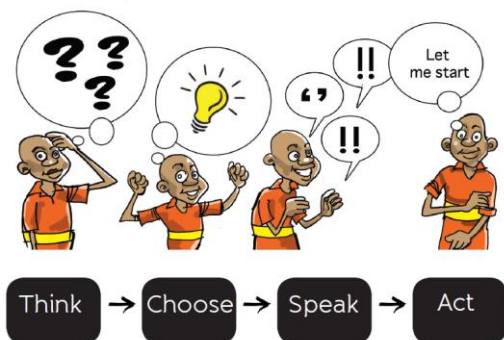
Activity 4.4.3: Movers Meeting

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 HIV/AIDS, addiction, building self-esteem, relationships, abortion)
3. Youth with epilepsy develop their own opinion
4. Youth with epilepsy have the courage to share their own opinion, even if they disagree with the majority



Every Saturday (except for the last Saturday of the month) we organize the Movers Meeting at our Training Centre. 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 Movers evaluate the last held actions and plan 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 topics such as epilepsy and related mental disorders, relationships, sex, drugs, alcohol, and peer pressure, how to achieve your dreams in life and how to feel good about

yourself. 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.

They discuss questions like:

1. When do you tell your colleagues, friends, family, partner that you have epilepsy?
2. Is epilepsy an excuse not to go to school or work?
3. What do you do if someone humiliates you, makes you angry or sad?
4. What is the role of girls and boys in a family?
5. What is rape? What do you do if it happens to you? What do you do when you see it happen?

The aim is that they do not only gain knowledge, develop an opinion, speak it up and act accordingly, but also to learn to appreciate themselves and daring to take space in a team. Every month the youth vote for the Mover of the Month. This youth gets Ksh 1,000 as a reward and their picture in the list of the Mover of the Month. This encourages them to put extra effort in developing their skills and to be a rolemodel to one another.

Results in 2019: The number of youth who attended the Movers Meeting and the Movers Picnic increased as the former Movers in training kept coming back to participate in the activities. The Movers also invited their friends who joined in the meeting and kept coming. Other stakeholders in epilepsy care also referred youth to the center to learn more and get a space to meet other youths. The youth actively prepared themselves by looking up information online and brought in grounded arguments for their opinions making the discussions and debates very lively. The youth also already engaged in talks about the topic of



discussion prior to the day of the meeting. While

the youth needed more time in the beginning of the year to speak up, already half way the year they actively contributed in sharing their personal views. Even those who did not speak English well were confident to express themselves in Swahili language. However, it remained important for the guides to keep an eye on the gender balance. Girls still needed more encouragement to speak as often as boys without hiding their beautiful smiles behind their hands. The guides also ensured those less educated and the slow learners got an opportunity to express

themselves too.

Follow up in 2020: This activity remains popular among the youth and is therefore high in the priority list for us to keep on offering it to the youth. It offers a good platform of improving both interpersonal and intrapersonal communication skills.

Activity 4.4.4: Movers Picnic

Objective: The youth with epilepsy practice their skills of working in a team where every participant is equally valued and involved in achieving the planned activities.



The last Saturday of the month is the Movers Picnic at the Arboretum Park. The activities of the picnic are organised by the youth themselves, which helps them to practice their skills in teamwork and to find a way to make one another feel safe in a team. The youth team receive Ksh 1,500 to buy snacks and drinks for the event. In addition the park now charges entry fees of Ksh 50 per person which is covered by YotM for the attendance of the youth in training plus those others who arrive first at the venue. In total 20 youth are covered.

Results in 2019: It was quite encouraging that even youth who had followed our trainings several years ago continued to attend the Movers Picnic. Their attendance enabled them to be rolemodels for the Movers in Training 2019 who saw how they could also make it a success after attending the training. NECC-doctors from various clinics too referred youth patients to attend the picnic in order to share and learn from the others.



Follow up in 2020: YotM continues to give the role to the youth in training to organise the Movers Picnic under guidance of the Mover of the Year (who is selected in December 2019). We will also cover the entrance fee for 20 youths instead. That is those in training scheduled and the others who keep time.

Activity 4.4.5: Parents Meeting

Objective: Parents offer guidance to their daughter and son 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 miss out on opportunities to strengthen their independence. To change this, we offer a monthly 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 specific topic under guidance of the trainer in Nairobi. Together they take conclusions how best they can encourage their child to live healthy and more independent. For this they make use of the manual which we developed in partnership with the parents and youth with epilepsy.

Results in 2019: Compared to 2018 where we had only two support groups (at YotM center and Kibera), in 2019 the parents meetings were organised at three different places as the clinic coach began another support group on 4th February at Baraka health center in Mathare. Therefore we reached out to 30 parents in total. The parents were so committed to the program and encouraged each other to observe time. The parents formed a Whatsapp group for easy communication on current issues affecting them.

The parents who met at the clinic continued with their table banking for the group. They weekly contributed Ksh 50 and gave the total to one member who returned the following month with an interest of Ksh 10 for every Ksh 50. This ensured the group continuity and a source of capital to start or boost their businesses. The clinic coach Beckham shared the idea of table banking to the Mathare team and they embraced it too.



Follow up in 2020: also in the upcoming year we will invite 10 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. We also plan to continue the support group at the two clinics with the guidance of the Movers Coach.

“Joining the support group at MSF kibera as a parent with an 11-year-old girl living with epilepsy is the best thing and decision that I will always cherish. Meeting people who share in my plight is so therapeutic that I always seek permission from work during clinic days not only to take my daughter for check up but to also meet these wonderful friends. From our interactions I have learned a lot and the table banking has enabled me start a green grocer for my elder daughter who now assists me with some cash at the end of the month to facilitate home budget.”

- Auma, parent of support group MSF Kibera epilepsy clinic, 2019.

Activity 4.4.6: Coaching at epilepsy clinics

Objective:

1. Clients with epilepsy and their caregivers understand their epilepsy and know how they can take good care of themselves
2. Doctors can attend to more clients during clinic days.

When people with epilepsy in Kenya go to a clinic for treatment, 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 of our peer educators at three clinics in Nairobi. In understandable language they pass over this knowledge. Therefore the doctor needs less time to help a patient, the waiting time reduces and the quality of care improves.

The peer educators are the trainees (see Activity 4.4.1: Train the Trainer) under guidance of a professional youth coach (the Mover of the Year of the last but one year). During the coaching of the clients they tackle 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 a seizure?
4. Lifestyle: what are the options for work and social life?

Results in 2019

Yotm introduced a new model for the Epilepsy Coaching which offered more youth in training the chance to further develop their skills as qualified coaches. Instead of one staff member performing this profession throughout, we gave the honour to the youth in training of the last but one year who received the Mover of the Year award. After one year of epilepsy education country wide, the Mover of the last but one year took up the duty of coaching the clients at the clinics as well as guiding the youth in training as they also practiced their skills as youth guides. There was also a bi-monthly visit to Tei wa Ngai Clinic in Matuu Machakos County in Eastern part of the Country upon request by the Catholic Sisters who run the clinic.



Follow up in 2020: also in the upcoming year we're offering 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 in Nairobi.

Activity 4.4.7: Train the Community Health Volunteers

Objective: Community Health Volunteers are well informed about epilepsy and utilise their knowledge as guides of people with epilepsy in their community.

During the awareness creation on epilepsy far away from our offices we came to realise that we need Community Health Volunteers (CHVs) to reach out to people who do not visit the health practitioners for conventional treatment. The CHVs have a chance to attend to the persons with epilepsy and their caretakers over a longer period of time and therefore assist them better in changing attitudes to make use of the required epilepsy care. Combining NECCs road shows (see activity 4.2.1), CHV-trainings and medical seminars (for training medics) have proved to provide all round results in improving the social participation and access to treatment on epilepsy. This year we have already covered Embu and Kitui and we will cover Kisii and Homabay.



We asked Community Health Volunteers the following questions:

1. How can you identify people with epilepsy in your community?
2. How can you encourage them to seek medical assistance at the right facility?
3. How can you guide them in becoming independent and prevent them from isolation?

Results in 2019: A total of 164 CHVs were trained. Out of the 164 only 8 (3 coordinators and 5 CHVs in the four Counties) had once attended a Non-Communicable Disease Seminar in which epilepsy was just one of the sub-topics of discussion. The rest knew very little about the facts on epilepsy. The seminars made great impact as the CHVs referred 204 persons living with epilepsy for medication in the facilities they were attached to as well as to others that provide epilepsy treatment.

Follow up in 2020: This year we wish to follow up with this activity. Our target is to reach to all the 41 Counties in Kenya. Having community professionals on matters of epilepsy will go along way in bringing persons living with epilepsy in close proximity to information. The support groups formed by the CHVs gives a forum to persons living with epilepsy and their caregivers to share their experiences, learn and consult and lobby for their rights. The training of CHVs also ensures continuity of epilepsy awareness in parts of the country as they CHVs work under the County government so it is a move to delegate this initiative to Counties. We also wish to invite at least 5 prison welfare officers to join in the CHV seminars every year.

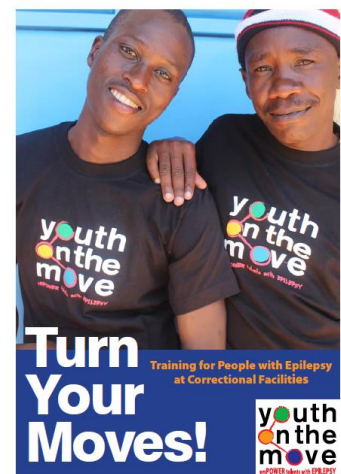


Activity 4.4.8: Turn your Moves

Objective:

1. People with epilepsy at prisons know the facts of epilepsy and how to effectively deal with their seizures
2. People with epilepsy in prison learn to effectively deal with aggression and peer pressure

In Kenya, more than 55,000 persons live in the prisons, nowadays called Correctional Facilities, and among them are people with epilepsy. The circumstances at the correctional facilities often trigger seizures, such as lack of sleep, lack of food and stress.



The social workers at the Nyeri Prisons encouraged us to meet with the people with epilepsy in prison. During this training they asked a lot of questions that we had not yet answered in our 'Let's talk Epilepsy' manual. Like, 'how can I avoid anxiety when I feel threatened by my fellow inmates?' Therefore we organised meetings in 2016 for them to share experiences and advice. We utilised this by writing a manual with them that has become a guideline for people with epilepsy at the correctional facilities countrywide. Professionals gave us their contributions as well, including a psychologist, neurologist, epileptologist, social workers, guards and policymakers of the Prisons Headquarters in Nairobi. The content has been endorsed by the government and was therefore approved for publication and dissemination in all Correctional Facilities in Kenya.

Results in 2019: The target group was inmates and prison staff especially those living with epilepsy and welfare officers in the selected cities for the Angaza Kifafa campaign of NECC (see activity 4.2.1). In 2019 YotM reached out to 4 correction facilities: Athi River prison, Embu prison, Kisii prison and Homabay prison. The number reached is tabulated below: The welfare officer in charge of Jamuhuri prison who followed keenly on the YotM activities on Facebook was impressed with the work at the other prisons and therefore contacted the organization and requested for a session with the inmates in his facility. See in the table below an extra prison.



| Prison | No with epilepsy trained | Total inmates trained | Total prison staff trained |
|---------------------|--------------------------|-----------------------|----------------------------|
| Athi River (2019) | 08 | 321 | 24 |
| Embu Prison (2019) | 04 | 200 | 06 |
| Kisii Prison (2019) | 13 | 800 | 35 |
| Homabay (2019) | 7 | 300 | 3 |
| Jamuhuri prison | - | 08 | 2 |
| TOTAL | 32 | 1629 | 70 |

Follow up in 2020: next year we are going to offer the training at Correctional Facilities where we're also going to hold the Road show with NECC, which is in Nairobi, Kiambu, Isiolo and Machakos in 2020.

Activity 4.4.9: Book club



Objective: Youth strengthen their English vocabulary and therefore improve their ability to express themselves verbally

We noticed that youth often face challenges in speaking English when they're in a team, mainly finding the right words to express their thoughts and feelings. Besides, the youth often think it's not cool to read. Therefore we decided to pay extra attention to encouraging youth to more actively read books to expand their vocabulary and knowledge, which also boosts their confidence. This year we received donations to purchase more books and engaged the youth to suggest books they want to read. The most preferred books were Michelle Obama's *Becoming* and Amolo Odinga's autobiography.



Results in 2019: The youth trainer adopted a new approach where the youth discussed a book they had previously selected to read for one hour in class before starting the normal routine. This motivated the youth to develop a reading culture which greatly boosted the confidence among the youth to speak English and borrow other books to read on their own at their free time. The story of *Rich Dad Poor Dad* by Robert Kiyosaki was the most popular book.

Follow up in 2020: also in the upcoming year we'll offer the book club again so that the youth are still encouraged to read and broaden their horizon. We plan to continue the approach of discussing a book for one hour before starting the normal class routine.

Activity 4.4.10: Movers Yoga

Objective: Youth learn to listen better to their body and to find a better balance which strengthens their confidence.

The Movers Yoga was initiated in 2011 in partnership with Afrika Yoga Project. The exercise is offered for one hour after classes. The youth note that yoga helps them to relax, to have a good concentration, it boosts their confidence and stimulates them to work well as a team. Yoga would also make them physically more stable and therefore contribute in reducing the number of seizures. This is because stress is one of the triggers of seizures, which is reduced once yoga is applied.



Results in 2019: This year the youth in training are very passionate about the exercise which makes them to even practice it at home.

"Knowing there is yoga session after classwork makes me concentrate more in class and actively participate for I know that after the mental engagement comes the relaxation of the mind, body and soul at yoga time. I love the combination and our yoga coach is just amazing with new moves every week."

- Clifford Brian Omondi, Mover in Training, 2019

Follow up in 2020: because of the popularity of the Movers Yoga, we plan to further the trainings in partnership with Hellen who is our former Mover in training in the year 2016.

Activity 4.4.11: Addiction Program

Objective: To create awareness on the causes and effects of substance and behavioural addictions for the prevention and control of it



One of the cartoons drawn by Baba Mdogo for the manual on addictions, July 2019

During the Movers Meetings the youth regularly shared their personal challenges to prevent or control addictions. They mainly shared about their challenges not to use alcohol and drugs and not to spend their money on betting or gaming. Therefore they proposed to learn more about it to prevent these addictions and to be encouraged to seek further professional assistance and support to manage the addictions.

Therefore three sessions were organised whereby youth with and without addictions have shared their personal experiences and ideas how to prevent and overcome the addictions. With the help of the cartoonist Bwana Mdogo drawings were made to convey their experiences. The experiences of the youth, the cartoons and the expertise of medics will be used for developing a manual with the basic knowledge on addictions and encouragement to seek professional guidance.



Follow up in 2020: this year we organise meetings for three groups of ten people who are battling addiction. Each group will attend four sessions at YotM's Training Centre where they will be taught about the basic facts on how to control addictions. During these sessions they will also be encouraged to share their personal experiences on how they developed the addiction. The aim is that this will be a stepping stone for them to seek further professional assistance.

Activity 4.4.12: Movers Cyber & Social Media

Objective:

1. Youth with epilepsy learn to make use of the computer
2. Youth with epilepsy share experiences with youth with epilepsy from other countries
3. Youth on the Move strengthens their financial independence



Youth on the Move opened a cyber cafe in 2008 to offer computer classes and internet access to the youths with epilepsy attending our activities. By learning to work on the computer, the youths create better chances at the labour market.

1: Access to knowledge and exchange of experiences via internet

The youth are encouraged to look up information online for their homework and for the Movers Meeting where they discuss a topic that's selected according to their desire. Once youth feel free to speak up their, they are also encouraged to share this internationally through social media like Facebook, LinkedIn and Twitter.



2: Online Epilepsy Education

To share the knowledge on epilepsy and to stimulate youth to share their personal experiences, James Munyao places twice per day a post on Youth on the Move's like page on Facebook and Twitter. Youth regularly approach YotM via social media to ask how they can take part in the movement and where they can get treatment. James actively communicates with them via social media and provides information how they can participate and where they can get medical help.

3: Income generation

The Movers Cyber offers more than opportunities for youth with epilepsy; it's also delivering income. Customers browse and our cyber assistants type documents, copy, bind and laminate files for them. This profit covers part of the costs of Youth on the Move.

Employees: the cyber café in Nairobi West is run by two cyber leaders. They offer support to youth in training and the customers. The financial administrator keeps track of the financial records that are also cross checked by an external auditor who delivers quarterly reports. This keeps us up to date about the results and whether we need to make any changes for smooth operation of our services.



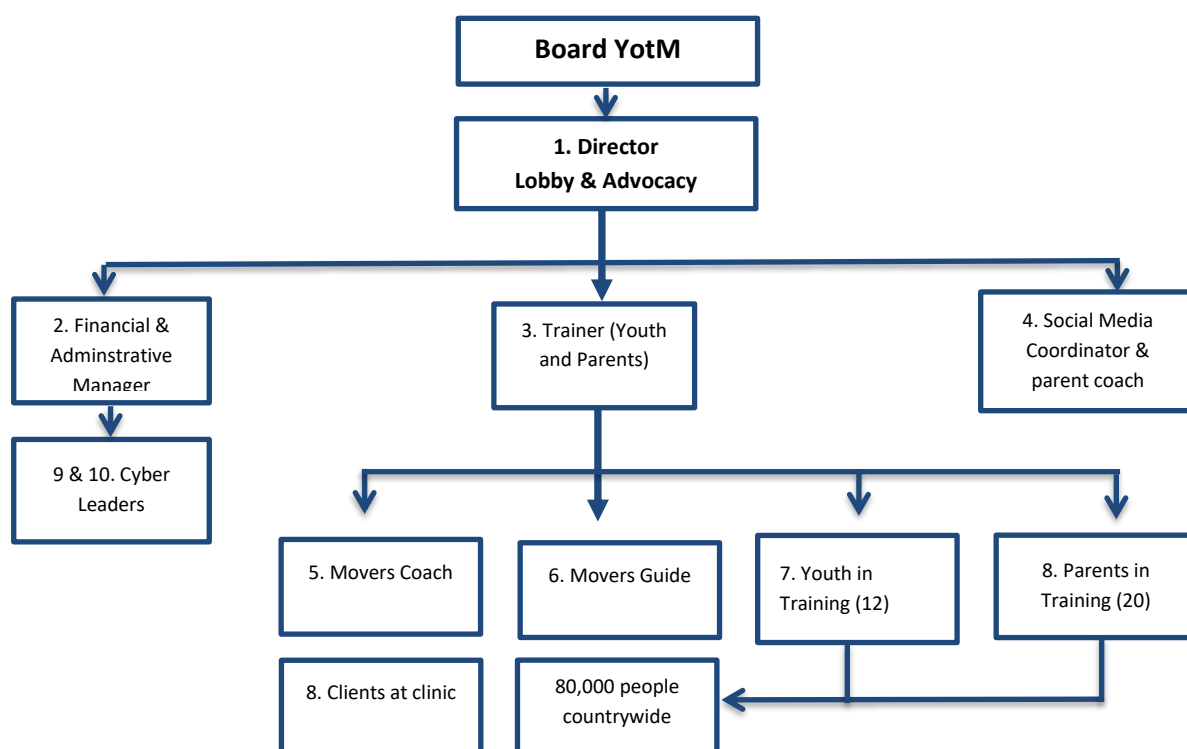
Results in 2019: The youth in training continued to enhance their computer skills, browse and interact with others in far places through the offered access to internet. They also made use of the Movers Cyber to do their homework. The former Movers also walked in to browse and catch up with the current issues. They also shared their knowledge with the current Movers in training.

The Movers Cyber was well visited by customers and the monthly average income was Ksh 175,000. However, in Kenya most people in business faced challenges of tough economic times especially in the month of April and May 2019. The same was witnessed in December as most people usually travel for holidays. This also brought YotM's income below Ksh 175,000 for those months.

Follow up in 2020: The Movers Cyber will continue to operate as a stable source of income and central meeting point of the former, current and upcoming Movers in training. We'll keep on availing our professional staff who offer support to both the youth and customers in learning how to utilise the knowledge and opportunities that internet offers.

5 Our staff

Youth on the Move started their activities as a response to the unmet needs of the youth with epilepsy and their proposal how to fulfil them. The aim was and remained for the youth with epilepsy to be the owners and implementers of the activities. They take up the duties of learning the skills as peer educators and thereafter reach out to people all over the country to educate them on epilepsy. They do this under guidance of professionals who share their skills to deliver quality education and guidance. The organisation is registered in Kenya and has board members assisting the staff to make sure that the services are according to the standards that the organisation has set.



1. Epillose Musimbi (Master Community Development): Director
2. Jane Wahome (BSc Business Administration): Financial Manager
3. Purity Sipilon (Community Health Worker, trainee YotM in 2012): Trainer & Parent Coach
4. Brenda Jepkorir: Social Media Assistant and parents trainer January to August 2019
5. James Munyao: Social Media Assistant September to December 2019
6. Leonard Beckham Ouma: Clinic Coach
7. Eunice Awinja (Movers Educator, Mover of the Year 2019 who was selected in Dec. 2018)
8. 12 Youth in Training
9. 30 Parents in Training
10. Haniph Asman: Cyber Leader
11. David Karanja: Cyber Leader

A Big Thank you from YotM Family for your Support!



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 in Kenya:

| | |
|-------------------|---|
| Florence Gichoya: | Chairperson; Journalist and student International Diplomacy |
| Epillose Musimbi: | Secretary (ex-officio, without vote); Director YotM Kenya |
| | Secretary National Epilepsy Coordination Committee |
| Richard Oduor: | Treasurer (writer and researcher) |
| Ngugi Mwenda: | Magistrate in Bungoma |

Board in the Netherlands:

| | |
|---------------------------|---|
| Josefien de Kwaadsteniet: | Chairperson: Trainer and Advisor at MDF Training & Consultancy |
| Tom van der Velpen: | Treasurer: communication expert |
| Karijn Aussems: | Secretary: researcher and lecturer at VUmc (medical humanities), former director Youth on the Move Kenya |

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 of Movers Exams in 2019 until October

| Tuesday class | Epilepsy | Culture & Identity | Coaching | Team-work | Youth Participation | Lifestyle | Entrepreneurship | Finals |
|----------------------|-----------------|-------------------------------|-----------------|------------------|----------------------------|------------------|-------------------------|---------------|
| Dennis | 83.5% | 99% | 92% | 84% | 86% | 91% | 93% | 98% |
| Vanile | 75.5% | 82% | 85.5% | 76% | 70% | 88% | 90% | 82% |
| Isaack | 99% | 96% | 94% | 99% | 96% | 100% | 99% | 100% |
| Zuhra | 95% | 89% | 90% | 89% | - | - | - | - |
| Chris | 50% | 70% | 40% | 45% | 49% | 70% | 60% | 45% |
| Berly | 97% | 94% | 100% | 90% | 81% | 100% | 92% | 100% |

| Wednesday class | Epilepsy | Culture & Identity | Coaching | Team-work | Youth Participation | Lifestyle | Entrepreneurship | Finals |
|------------------------|-----------------|-------------------------------|-----------------|------------------|----------------------------|------------------|-------------------------|---------------|
| Rosemary | 80% | 85% | 88% | 89% | 77.5% | 98% | 72% | 98% |
| Brian | 100% | 93% | 96% | 92% | 91.5% | 99% | 96% | 100% |
| Mercy | 85.5% | 89% | 90% | 99% | 90% | 98% | 80% | 98% |
| Clifford | 80.5% | 95% | 86% | 89.5% | 68% | 88% | 72.5% | 86% |
| Lucky | 45% | 70% | 36% | 40% | 56% | 69% | 30% | 40% |
| Mare | 93% | 96% | 93% | 97% | 90% | 98% | 97.5% | 90% |

| | Epilepsy | Culture and Identity | Coaching | Teamwork | Youth Participation | Lifestyle | Entrepreneurship | Final |
|----------------------|-----------------|-----------------------------|-----------------|-----------------|----------------------------|------------------|-------------------------|--------------|
| Highest Marks | 100% | 99% | 100% | 99% | 96% | 100% | 99% | 100% |
| Lowest Marks | 45% | 70% | 36% | 40% | 49% | 69% | 30% | 40% |
| Average | 82% | 88.2% | 82.5% | 81.7% | 77.7% | 90.8% | 80.1% | 85.1% |

Appendix 3: Epilepsy Education Attendance Summary (Jan –Dec) 2019

| PLACE/PROVINC E | COUNTY | VENUE | MONTH | TRAINERS | NO. OF PEOPL E REACH ED |
|--------------------|--------------|----------------------------------|-----------------|-----------------|-------------------------------------|
| Kitui | Kitui | Ikandani pri | January | Beckham/Eunice | 380 |
| | | Ikutha boyz | | | 356 |
| | | Kasaini pri | | | 250 |
| | | Ngomeni pri & sec | | | 400 |
| Machakos | Matuu | Matuu Clinic | | Beckam | 150 |
| | Kangundo | Kangundo Women Group | | Purity | 30 |
| | Katangi | Katangi Women Group | | Purity/ Eunice | 29 |
| | Athiriver | St. Jude Dispensary | | Eunice | 60 |
| | | St. Jude Special Group | | Purity | 15 |
| Nairobi | Githurai | Shining Star Learning Centre | | Beckam / Eunice | 120 |
| | Mukuru Slums | St. Mary's Support Group | | Purity / Eunice | 56 |
| | | St. Mary's Clinic | | Purity/ Eunice | 42 |
| | Baraka | Baraka Clinic | | Beckam/ Youths | 600 |
| | Kibera | Kibera MSF Clinic | | Beckam/ Beckham | 320 |
| | CBD | St. Johns Ambulance | | Atito/ Youths | 110 |
| Mombasa | Mombasa | Shanzu chief baraza | February | Beckham/Eunice | 200 |
| | | Casurina children home utange | | | 140 |
| | | New hope childrens centre utange | | | 300 |
| | | Mtwapa mixed sec | | | 360 |
| | | Mtwapa elite academy | | | 200 |
| Machakos | Machakos | Baptist pri | | Beckham/Dennis | 390 |
| | | Kakinduni pri | | | 459 |
| | | Embui pri | | | 400 |
| | | Makutano pri | | | 395 |
| | | Watheia pri | | | 900 |
| | | muthwani pri&sec | | | |

| | | | | | |
|-----------------------------|--------------|-------------------------------------|-------|-----------------|--------|
| Nairobi | Nairobi | Brook field academy | | Beckham/Eunice | 50 |
| | | Baraka academy | | | 160 |
| | | Little prince academy | | | 200 |
| | | Bridge international academy. | | | 120 |
| | | Kya Maiko Youth Group | | | 600 |
| | | Kahawa West Pri | | | 90 |
| | | Waithaka Academy | | | |
| | CBD | St. Johns Ambulance | | Atito/ Youths | 100 |
| | Baraka | Baraka Clinic | | Beckam/ Youths | 500 |
| | Kibera | Kibera MSF Clicin | | Beckam/ Youths | 210 |
| Makueni | Emali | Kitambui Women Group | | Purity | 50 |
| | | Catholic Women Group | | | 85 |
| | | AIC Kyatumbui | | | 260 |
| | | Mutuluni Pri | | | 499 |
| Nyanza | Nyakatch | Kibwon pri | March | Eunice/Mercy | 185 |
| | | Holo ngege baraza | | | 56 |
| | | Siany baraza | | | 60 |
| | | Sigoti baraza | | | 89 |
| Makueni | Sultan Hamud | Ilaka Group | | Purity | 52 |
| | | Kya wautu youth Group | | | 50 |
| Total no. of People reached | | | | | 10,078 |
| Kakamega | Kakamega | ST Gerald shitao primary school | | Eunice/Rosemary | 535 |
| | | ST Gerald shitao county polytechnic | | | 48 |
| | | Shitao community school | | | 667 |
| | | Shieywe secondary school | | | 482 |
| | | Shivakala primary school | | | 429 |

| | | | | | |
|----------------|----------------|------------------------------------|--------------|-------------------|-----|
| | | Matende primary school | | | 200 |
| | | Kakamega township primary school | | | 520 |
| Nairobi | Nairobi | Hamza rise and shine youth group | | Purity/Beckham | 20 |
| | | Hamza Pentecostal church | | | 100 |
| | | Hamza PAG church | | | 50 |
| | | Ngongina Youth Group | | Eunice/ Clifford | 30 |
| | | Madaraka Group | | Beckam/ Vanile | 20 |
| | | Baba Ndogo Group | | Eunice/ Mare | 16 |
| | | Bridge International Academy | | Beckam/ Isaack | 156 |
| | | Mathare Academy | | Eunice/ Beckam | 165 |
| | | Citrus Youth Group | | Beckam/ Rebecca | 22 |
| | | Kawangware Pri | | Eunice / Berly | 200 |
| | | Sunshine Academy Kayole | | Eunice/ Dennis | 166 |
| | Mathare | Baraka clinic | | Beckam/ Youths | 700 |
| | Kibera | MSF Kibera Clinic | | Beckam/ Youths | 365 |
| | CBD | St. Johns Ambulance | | Atito/ Youths | 120 |
| | Embu | Kiambiti Maruru youth Group | | Eunice / Vanile | 20 |
| | | Kirurumo Pri | | | 300 |
| | | Join the Troop Group | | | 50 |
| | | Mangoo' Group | | | 36 |
| Nairobi | Kibera | St. Peters Youth Camp | April | Beckam / Clifford | 60 |
| | | Kibera Soweto Resource Centre | | | 30 |
| | Baraka | Baraka Clinic | | Beckam/ Youths | 755 |
| | Kibera | Kibera Clinic | | Beckam / Youths | 398 |

| | | | | | |
|------------------------------------|-----------|---------------------------------------|------------|-------------------------------|---------------|
| | CBD | St. Johns Ambulance | | Atito/ Youths | 160 |
| Homabay | Ndhiwa | SDA Church Ndhiwa | | Eunice / Brian | 200 |
| | | Mahakha youth Group and PAG Church | | | 400 |
| | | Otiende Camp | | | 150 |
| | | Bhuktuzi Organization and Camp | | | 89 |
| | | | | | |
| <u>Kajiado</u> | Kitengela | St Monica Nookopir | | Purity / Eunice | 216 |
| | | Catholic Women Association | | Eunice / Mare | 29 |
| | | Olerai Camp | | Eunice | 84 |
| <u>Busia</u> | Butula | Flankimart Taida Spiritual Church | | Eunice/ Brian | 120 |
| | | Shitsitswi ACK Church and Full Gospel | | | 130 |
| | | Chief Baraza | | | 59 |
| | | Switstwi Group | | | 19 |
| | | Emutaire Youth Group | | | 60 |
| <u>Machakos</u> | Athiriver | PAG Athiriver | | Eunice / Berly | 120 |
| | | Deliverance Youth Camp | | Eunice / Mercy | 83 |
| | | Makadara Youth Group | | Eunice / Rosemary | 150 |
| Taita Taveta | Undanyi | Disability Group | | Purity | 46 |
| Nairobi | Langata | Langata High | May | Beckam | 289 |
| Total No. of People reached | | | | | 19,142 |
| Machakos | Wamuyu | St. johns Kangii Sec | | Beckam/ Isaack | 300 |
| | | St. johns Kangii Pri | | | 350 |
| | | Kya Wango Pri | | | 600 |
| | | Kiuanzukini A.I.C Sec | | | 360 |
| | | Ilani Pri | | | 266 |
| | | Maweale Pri | | | 370 |
| | | GK Athiriver Prison | | Epillose/ Brian/ Beckam/ Mare | 10 |

| | | | | | |
|----------------|--------------|--------------------------------|-------------|---------------------|-----|
| Nairobi | Nairobi | Claire's Community School | | Eunice / Vanile | 300 |
| | | Baba Ndogo Sec | | Eunice/ Dennis | 80 |
| | | St. Maries Karis | | Eunice/ Brian | 150 |
| | | PAG Kariombagi Sch | | Eunice / Berly | 100 |
| | | Gifted Hands Pri | | Beckam/ Berly | 89 |
| | | Baraka Clinic | | Beckam and Youths | 750 |
| | | MSF Kibera Clinic | | Beckam and Youths | 400 |
| | | St. Johns Ambulance | | Atito and Youths | 120 |
| | | Sunshine High School | | Beckam/ Eunice | 300 |
| | | Langata High school | | Beckam/ Clifford | 201 |
| | | Shadrack High | | Eunice/ Zuhra | 100 |
| Nakuru | Naivasha | Jitetee Group | | Purity/ Eunice | 30 |
| | | Wamama wa Maendeleo | | | 23 |
| | | Tumaini Youth Group | | | 56 |
| | | Baraza ya chief | | | 56 |
| Kajiado | Kajiado | Noongopir Women Group | | Purity/Vanile | 41 |
| | | St. Peter Olelai Group | | | 15 |
| Makueni | Sultan Hamud | Kya Kyalo Group | | Purity | 23 |
| | | Matulungi Special Group | | | 29 |
| | | Malaani Sec | | | 159 |
| | | Katangini Polytechnic | | | 85 |
| Nairobi | Nairobi | Mama Lucy Neighborhood Academy | June | Beckam/ Berly | 75 |
| | | Tumaini Academy | | Eunice/ Christopher | 59 |
| | | Kibera Soweto Group | | Beckam/ Clifford | 38 |
| Busia | Busia | Butula Special School | | Eunice/ Zuhra | 62 |
| | | Musianda Girls | | | 320 |
| | | Mulendwa Academy | | | 200 |

| | | | | | |
|------------------------------------|------------|-----------------------------|------|-------------------|---------------|
| | | Mungoma Praise Centre | | | 27 |
| Total No. of People Reached | | | | | 25,286 |
| Nyahururu | Laikipia | Raichiri Secondary | | Eunice / Rosemary | 660 |
| | | Raichiri primary | | | 700 |
| | | Kirera Secondary | | | 356 |
| | | Kirera Primary | | | 300 |
| | | Spring Preparatory | | | 157 |
| | | Ndogino Primary | | | 400 |
| | | Ngaindethia Primary | | | 589 |
| | | Ngaindethia Secondary | | | 568 |
| Nairobi | Huruma | St. Claires academy | | Beckam/ Clifford | 200 |
| | Kayole | Trickle up Youth CBO | | Purity/ Beckam | 59 |
| | Mathare | Baraka Clinic | | Beckam and Youths | 680 |
| | Kibera | Kibera Clinic | | Beckam and Youths | 380 |
| | CBD | St. Johns Ambulance | | Atito and Youths | 120 |
| | Langata | Langata Special Group | | Purity | 26 |
| | Baba Ndogo | Baba Ndogo Academy | | Eunice / Zuhra | 166 |
| | Dandora | View Point Academy | | Eunice/Clifford | 230 |
| Machakos | Matuu | Matuu Clinic | | Beckam/ Vanile | 65 |
| Siaya | Ugunja | Ugunja High School | | Beckam / Dennis | 300 |
| | | Mban Catholic Parish | | | 187 |
| | | Masamra Primary | | | 669 |
| | | Siror Primary | | | 400 |
| | | St. Edward Secondary | | | 158 |
| | | Ulumba Primary | | | 591 |
| | | Anyiko Primary | | | 305 |
| | | Anyiko Secondary | | | 93 |
| Kisii | Nyamira | St. Pancras Mixed Secondary | July | Beckam/ Isaack | 296 |

| | | | | | |
|-----------------------------|-----------|--|--------|----------------------|--------|
| | | Kiong'ong'i D.O.K Primary | | | 520 |
| | | Nyamisaro D.O.K Primary | | | 455 |
| | | Riamoraa Academy | | | 448 |
| | | Getome D.O.K Primary | | | 300 |
| | | Nyaguku Secondary | | | 250 |
| Machakos | Matuu | Matuu seminar for Secondary, Primary and Special school Teachers | | Purity/ Epillose | 40 |
| Nairobi | Langata | Langata Youth Group | | Beckam/Eunice/ Zuhra | 29 |
| | Kayole | Kayole Resource Centre | | Purity/ Beckam | 33 |
| | Baraka | Baraka Youth Group | | Beckam/Berly | 59 |
| | Roysambu | Lucky Summer Academy | | Eunice/ Christopher | 164 |
| | Kibera | MSF Kibera | | Beckam and Youths | 120 |
| | Baraka | Baraka Clinic | | Beckam and Youths | 400 |
| | CBD | St. Johns Ambulance | | Atito and Youths | 169 |
| Total No. of People Reached | | | | | 36,928 |
| Kajiado | Kiserian | Kiserian Olerai Group | | Purity/ Eunice | 160 |
| Makueni | Kalimbini | Kalimbini Primary | | Eunice/ Vanile | 750 |
| | | Kateiko Youth Group | | | 60 |
| | | Munaa Secondary | | | 401 |
| | | Matwikuni Youth Group | | | 39 |
| | | ACK Kilimbini | | | 192 |
| Nairobi | Embakasi | Kwa Maiko Group | August | Beckam/ Bryan | 36 |
| | | Dandora Special Group | | Purity | 15 |
| | | Kariombagi PAG Church | | Eunice/ Berly | 149 |
| | Kibera | MSF Kibera | | Beckam and Youths | 90 |
| | Baraka | Baraka Clinic | | Beckam and Youths | 360 |
| | CBD | St. Jonhs Ambulance | | Atito and Youths | 159 |

| | | | | | |
|-----------------------------|----------|-----------------------------|-----------|------------------------|--------|
| Machakos | Joska | Joska Youth Group | | Beckam/ Dennis | 42 |
| | | Malaa Youth Group | | Beckam/ Vanile | 59 |
| Kisii | Nyamira | Kioge Girls Staff Training | | Beckam/ Clifford | 26 |
| | | Kioge Youth Camp | | | 294 |
| | | Isena Girls Mission Seminar | | | 313 |
| | | Omoreba SDA Church | | | 189 |
| | | Sengera Parish Women Group | | | 158 |
| Kitui | Mlango | Mwamba Support Group | | Beckam/ Vanile | 41 |
| | | Mwamba Youth Camp | | | 847 |
| | | AIC Mwiwe Church | | | 131 |
| | | Mama Wasafi Women Group | | | 54 |
| | | Kateiko Youth Group | | | 37 |
| | | Ingusya Episcopopol Church | | | 125 |
| | | Ikutha Group | | | 59 |
| | | | | | |
| Nakuru | Naivasha | Little Friends Organization | | Eunice/Rosemary/ Bryan | 109 |
| | | Vijana Youth Group | | | 21 |
| | | Lake Naivasha Youth Camp | | | 350 |
| | | Koibeiyon Youth Group | | | 38 |
| | | Masare Group | | | 89 |
| | | Shinda Ushide Youth Group | | | 57 |
| Busia | Ugunja | Butula Group | | Purity / Zuhra | 69 |
| | | Leio Maria Group | | | 78 |
| | | Funyula Camp | | | 289 |
| Total No. of People Reached | | | | | 42,125 |
| Siaya | Oyugis | Orera primary | September | Beckam/ Mare | 600 |
| | | Kagonda Primary | | | 952 |
| | | Orera Mixed Secondary | | | 500 |
| | | Ponge Primary | | | 987 |

| | | | | | |
|----------|------------|--------------------------|---------|-------------------|-----|
| | | Ponge Lutheran Secondary | | | 254 |
| | | Kadongo Chief Baraza | | | 160 |
| Nairobi | Kibera | Our Lady of Quadelepe | | Beckam /Clifford | 239 |
| | Joska | Joska Group | | Purity | 62 |
| | Makadara | Shauri Moyo Group | | Purity / Beckam | 45 |
| | Embakasi | Utawala Academy | | Eunice/ Berly | 167 |
| | | Utawala Special Group | | Purity | 39 |
| | Baba Ndogo | Mt. Tree Academy | | Eunice/ Vanile | 188 |
| | Makadara | Bahati Academy | | Eunice / Dennis | 176 |
| | Embakasi | Baba Ndogo Group | | Beckam / Brian | 87 |
| | Kibera | MSF Kibera | | Beckam and Youths | 100 |
| | CBD | St. Johns Ambulance | | Atito and Youths | 189 |
| | Baraka | Baraka Clinic | | Beckam and Youths | 459 |
| Kitale | Kiminini | Rayzon Academy | | Beckam/ Clifford | 200 |
| | | High Top Preparatory | | | 400 |
| | | St. John Catholic | | | 239 |
| | | Kajimbra Primary | | | 974 |
| | | Bondeni Group | | | 19 |
| | | Kiminini Primary | | | 644 |
| Kisii | Nyanchwa | Entago Secondary | | Eunice/ Mercy | 326 |
| | | Etiero Girls | | | 300 |
| | | Nyanguso Primary | | | 678 |
| | | Nyanchwa Secondary | | | 480 |
| | | Sameti High | | | 269 |
| | | Getembe Primary | | | 297 |
| | | Duru Primary | | | 500 |
| | | Duru Secondary | | | 359 |
| Machakos | Matuu | Clinic in Matuu | October | Beckam / Dennis | 80 |
| Nairobi | Kayole | St. Peters Kayole | | Beckam/ Isaack | 126 |

| | | | | |
|-------------|-----------|----------------------------------|--------------------|-----|
| | Dagoretti | Riruta Group | Eunice/ Berly | 65 |
| | Kibera | Kibera Little Angels | Beckam/ Christoper | 78 |
| | Embakasi | Embakasi Primary | Eunice / Beckam | 548 |
| | | Dandora Group | Beckam / Mercy | 29 |
| Migori | Rongo | Rongo SDA Church | Beckam/ Mercy | 155 |
| | | Rongo PAG Church | | 67 |
| | | Uriri Primary | | 401 |
| | | Nyalenyi Group | | 45 |
| | | Kobeo Boda boda Group | | 30 |
| | | Special Way Makers group | | 64 |
| | | St. Joseph Catholic | | 93 |
| | | Martin Luther Academy | | 200 |
| | | One stop Group | | 67 |
| | | | | |
| Makueni | Kalawa | Kituu cha Mundu Muka Women Group | Eunice / Rosemary | 30 |
| | | Kitandi Primary | | 604 |
| | | Kitandi Secondary | | 409 |
| | | Mbulika Secondary | | 312 |
| | | Kitandi Youth Group | | 69 |
| | | Mbangula Primary | | 400 |
| | | | | |
| Uasin Gishu | Eldoret | Langas Primary | | 820 |
| | | Mile Nne Primary | | 448 |
| | | Kapsoya Primary | | 609 |
| | | Jua Kali Primary | | 611 |
| | | Eldoret Women Group | | 85 |
| | | Central Secondary | | 334 |
| | | Chupkoilel Secondary | | 355 |
| | | | | |
| Vihiga | Mbale | Mudasa Primary | Beckam / Brian | 414 |
| | | St. Elizabeth Girls | | 208 |

| | | | | | | |
|-----------------------------|-----------|------------------------------|--------------|--------------------|--------------|-----|
| | | Vigina Primary | | | 145 | |
| | | Khuyerere Secondary | | | 134 | |
| | | Start Kizeh Secondary | | | 95 | |
| | | Mulundu PAG | | | 38 | |
| Total No. of People Reached | | | | | 61,182 | |
| Nairobi | Makadara | Makadara youth Camp | November | Eunice | 322 | |
| | | Shauri Moyo Sisters Group | | Purity | 259 | |
| | | Mathare youth camp | | Beckam/ Mercy | 365 | |
| | | Kibera group | | Eunice/ Beckam | 68 | |
| | | Highrise Special Group | | Purity/ Eunice | 43 | |
| | Baraka | Baraka Clinic | | Beckam / Youths | 400 | |
| | Kibera | MSF Kibera | | Beckam/ Youths | 70 | |
| | CBD | St. Johns Ambulance | | Atito/ Youths | 69 | |
| | Kisumu | Sondu | | Miriu Group | Purity Beryl | 100 |
| | | | | Naki Special Group | | 36 |
| Rakwara boy caring Centre | | | | 195 | | |
| Nyabondo Youth Camp | | | | 323 | | |
| Kisii | Taracha | Birongo group | Beckam/Bryan | 88 | | |
| | | Keumbu Dispensary | | 108 | | |
| | | Taracha Disability Group | | 99 | | |
| | | Nyakacho Disability forum | | 159 | | |
| Taita taveta | Mwatate | Kapsangare Dispensary Group | Purity/Mercy | 250 | | |
| | | Manyatta Jillo Health Centre | | 189 | | |
| | | Modambogho Youth Camp | | 364 | | |
| Kisii | Nyamemiso | Nyamemiso Group | December | Beckam / Dennis | 30 | |
| | | Gekarange Group | | 18 | | |
| | | Mashauri Group | | 29 | | |

| | | | | | |
|-----------------------------|---------|-----------------------------|--|---------------|--------|
| | | HappinessYouth Group | | | 52 |
| | | Nyamisero Elderly Group | | | 22 |
| Total no. of People Reached | | | | | 64,840 |
| Bungoma | Webuye | Nabuyole Group | | Eunice/ Brian | 20 |
| | | Lugulu Dispensary | | | 56 |
| | | City Harvest Church | | | 40 |
| | | Kiigumba Elderly | | | 19 |
| | | PAG Malakisii Special Group | | | 23 |
| | | Presbytery Group | | | 31 |
| | | Neema Special Group | | | 20 |
| | | Young Girls Group | | | 29 |
| Kakamega | Lurambi | Shisumu Youth Group | | Eunice / Mare | 28 |
| | | World Centre Group | | | 54 |
| | | Oasis of Grace Church | | | 90 |
| | | Emaholi Catholic | | | 156 |
| | | Makhokho Friends Group | | | 47 |
| Nairobi | Baraka | Baraka Clinic | | Beckam | 280 |
| | Kibera | MSF Kibera | | Beckam | 40 |
| | CBD | St. Johns Ambulance | | Atito | 34 |
| Total people reached: | | | | | 65,807 |

Appendix 4: Youth on the Move's Partners

Youth on the Move actively partners with stakeholders in Kenya and the Netherlands. Below we give you a description of the stakeholders we involve in meeting our objectives:

IBE and ILAE: International Bureau for Epilepsy and International League Against Epilepsy are two international institutions who involve us in organizing their activities for the African Epilepsy Congress. IN 2012 our youth were invited to launch the event when the Kenyan Minister of Health Anyang' Nyong'o was present.

NECC: This is the National Epilepsy Coordination Committee which we have initiated in partnership with all other stakeholders in epilepsy care, including the Ministry of Health. It is registered as a society and acknowledged as a government body. As members we utilise NECC as a platform to network and partner with the various stakeholders, including Bank of Africa who is one of NECCs sponsors.

KSE: Kenya Society for Epilepsy is a board of doctors with expertise on epilepsy directed by Professor Kioy, a neurologist. Professor Kioy is advisor for Youth on the Move and always available to give feedback on the contents of the educational materials from Youth on the Move.

Kawe: Kawe has three clinics for people with epilepsy and provides subsidized drugs. They allow our youth with epilepsy to offer coaching to their clients, as they refer them to our office.

FPE: Foundation for People with Epilepsy is an NGO that offers epilepsy care in Malindi. Their doctors offer us medical advice in our awareness creation and guidance of youth with epilepsy.

Matuu Catholic Church Machakos County: the church runs Tei wa Ngai epilepsy clinic which attends on average per month 90 patients. Youth on the Move partners with the clinic which is run by catholic sisters of mercy to educate patients bimonthly and also train their community health volunteers and teachers of special needs.

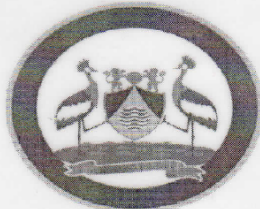
Sanofi: this is one of the Kenyan pharmaceutical companies, who actively contribute in our awareness creation by providing us comic books "We'll make it", which is a story about a boy with epilepsy who finds ways how to effectively live beyond it.

Kenya Prisons Service: We partner with them in training and guiding inmates living with epilepsy. They gave permission to the trainers to meet the inmates and to take part in developing the content of the manual.

County Governments: The Community Health Volunteers of the County Governments are trained by YotM and thereafter contribute in empowering their members of public living with epilepsy.

Appendix 5: Recommendation Letters of the Kenyan Government

NAIROBI CITY COUNTY



EDUCATION, YOUTH AFFAIRS AND SOCIAL SERVICES

✓ TO THE DIRECTOR
YOUTH ON THE MOVE
EMPOWER TALENTS WITH EPILEPSY
P.O BOX 20689-00100
NAIROBI

FROM: SENIOR EDUCATION OFFICER'D'

REF: GL/NC/485 B/26

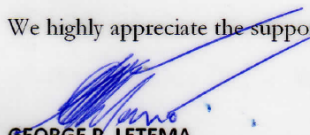
DATE: 10TH February, 2016

RE: EPILEPSY AWARENESS CREATION

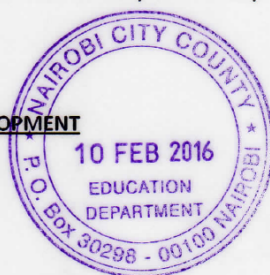
Your letter dated **Friday, January 22, 2016** on the above please refer.

Your request to visit the schools (list attached) is hereby granted upon your visit; please forward your report to this officer.

We highly appreciate the support you offer to the youth in City.


GEORGE P. LETEMA
SENIOR EDUCATION OFFICER DEVELOPMENT

Cc Director Education Department



MINISTRY OF INTERIOR & CO ORDINATION OF NATIONAL
GOVERNMENT
STATE DEPARTMENT OF CORRECTIONAL SERVICES
KENYA PRISONS SERVICE

Telegrams: "COMPRISONS" Nairobi
Telephone: +254 02 2722900-6
E-mail Comprisons@yahoo.com



PRISONS HEADQUARTERS
P.O.BOX 30175-00100
NAIROBI

Ref. No. PRIS 10/1/VOL.VII/68

Date: 8th February, 2019

0712623681 - Musimbi

The Program Manager
Youth on the move
Empower talents with
Epilepsy
P.O Box 20689 - 00100
Nairobi



26/6/2019

Re: Request to carry out epilepsy sensitization in Correction facilities

I am in receipt of your letter dated on 10/1/2019 on the above.

I would like to acknowledge receipt of your reports on your sensitization in Kitui, Kitale and Kericho.

I realized that you were able to bring out issues on epilepsy which many people are not aware. Bring out on what it is, the causes, the types, treatment and managing the conditions that come with it. It was very important. I learnt a lot from the report too.

From the above your request to hold sensitization on epilepsy in Athi River Prison on April, Embu Prison in May, Kisii in July and Homabay in September 2019 has been approved by the Commissioner general.

I recommend that you visit the institutions in advance for logistical planning to make the Program a success. Its is a very important Program.

MARY N. KHAEMBA

Mary Khaemba, (OGW)

Director, offender correction & Rehabilitation

FOR: COMMISSIONER GENERAL OF PRISONS

Madam Apelles - Kisii Prison (women)
0720 22 45 90.

MINISTRY OF INTERIOR & CO ORDINATION OF NATIONAL
GOVERNMENT
STATE DEPARTMENT OF CORRECTIONAL SERVICES
KENYA PRISONS SERVICE



Telegrams: "COMPRISONS" Nairobi
Telephone: +254 02 2722900-6
E-mail Comprisons@yahoo.com



PRISONS HEADQUARTERS
P.O.BOX 30175-00100
NAIROBI

Ref. No. PRIS 10/1/VOL.VII/68

Date: 8th February, 2019

The Program Manager
Youth on the move
Empower talents with
Epilepsy
P.o Box 20689 – 00100
Nairobi

OFFICER IN CHARGE
G.K. PRISON KITENGELA
P.O. Box 32, KITENGELA
26/4/2019

Re: Request to carry out epilepsy sensitization in Correction facilities

I am in receipt of your letter dated on 10/1/2019 on the above.

I would like to acknowledge receipt of your reports on your sensitization in Kitui, Kitale and Kericho.

I realized that you were able to bring out issues on epilepsy which many people are not aware. Bring out on what it is, the causes, the types, treatment and managing the conditions that come with it. It was very important. I learnt a lot from the report too.

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Director, offender correction & Rehabilitation