

Sharecare Ghana

Sharecare4u 

Annual Report for the
Year ended 2018

Sharecare Ghana is an association of people with autoimmune and neurological conditions, including families and caregivers. The association, founded in 2006, was registered in November 2007 as a non-profit organization, and launched in 2008.

Charity Registration Number : CG 094052017

TIN : C0009300252

Social Welfare Reg. Number : DSD 3972

AMA Registration Number : A.026/10/596

Registered Address : P.O. Box CT 4910
Cantonments
Accra
Ghana

Director : Nana Yaa Agyeman

Executive Council : Doris Ahiney Armar - Chairperson
Rosaelyn Ekua Adadzewa Otoo
Adwoa Sey
Farida Bedwei
Nana Akwasi Awuah
Nana Yaa Agyeman

Company Secretary : Joseph Kwasi Amegah Gadagbui

Bankers : GCB Bank Ltd

Auditor/Accountant : Portfolio Financial & Management Systems

Broad Objectives : To create awareness about autoimmune and neurological conditions; support and advocate for people with these conditions and promote research into these conditions and the disabilities they cause.

MESSAGE FROM THE DIRECTOR

We are getting desperate! Liliane Foundation has stopped supporting SWEB Foundation, meaning a substantial reduction in funds for our community-based rehabilitation (CBR) programme. Aviation Alliance Ltd. support ended in 2018. How do we continue to support Mobile Physio for needy families to access therapy at the Sharecare Rehabilitation Centre? How do we continue to pay allowances to the physiotherapists and social workers? How can we pay commercial rent for the premises and how can we get more space for the growing number of children with disabilities coming in for therapy?

For sustainability, we have put in a request to the National Council on Persons with Disability (NCPD) and the Ministry of Gender, Children and Social Protection to adopt our centre as the assessment centre for Osu Klottey, in line with the Disability Law of Ghana. We are already doing mobility, sensation and speech assessment and therapy, and would add on sight and hearing assessment. We expect that we will be granted accommodation by the State if our request is approved, and that would reduce the financial load considerably, and free us to source funds for the therapies and allowances.

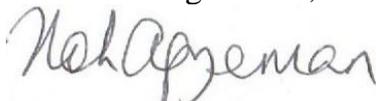
Activities for 2018 went very well with the support of SWEB Foundation/Liliane Foundation, EurHope, Ghanaman CRG Trust Fund, USAID, Aviation Alliance Ltd., Ghana Federation of Disability Organizations, International Alliance of Patients Organizations and a number of individuals. We are grateful for this support and hopeful that there will be more of such generous support in the years ahead.

We have renewed our engagement with the Noguchi Memorial Institute for Medical Research in our continuing search for answers to the causes and triggers of autoimmune disease conditions with hope for an end to these diseases.

We welcome Nana Akwasi Awuah, a renowned legal professional, to our Executive Council, knowing that he brings new life and fresh ideas to the Executive Council.

Ayekoo to the entire membership, Executive Council, management, staff, and physiotherapists, for keeping the organization alive.

With sincere gratitude,



Nana Yaa Agyeman

REVIEW OF YEAR 2018

1, ACTIVITIES: CBR, ADVOCACY AND AWARENESS CREATION

SHARECARE REHABILITATION CENTRE

The Sharecare Rehabilitation Centre continued to provide physiotherapy three times a week; and six of the children attended various schools, four supported by SWEB Foundation, and two by Sharecare Ghana. Liliane Foundation which supports SWEB Foundation however ended the sponsorship at the end of 2018.

The centre was unable to fully employ the social workers and physiotherapists who are currently only receiving allowances. Adequate funds would enable the centre to employ a speech therapist and therapy sessions would increase to five days a week. The Audiology Department of the University of Ghana was approached for speech therapy interns, which is receiving attention.

The space at the centre is woefully inadequate, and expensive to rent. A request was submitted for the National Council on Persons with Disability and Ministry of Gender, Children and Social Protection to adopt the Sharecare Rehabilitation Centre as the assessment centre for the Osu Klottey District under the Disability Law of Ghana. This was still being pursued at the end of the year and is of highest priority in the year ahead.

The centre will continue to provide physiotherapy three times a week accompanied with home and school visits until finances make it possible to increase the therapy days.

SUPPORT GROUPS

Parents Support Group

The parents support group (mostly mothers) began two projects in 2018; training in and production of liquid soap, and production of physiotherapy devices using paper-based technology.

The liquid soap project sponsored by Ghanaman CRG Trust Fund was to equip the mothers with income generating skills to earn incomes to provide for their children. Out of the proposed 20, 14 mothers were trained, but only five g were seriously producing and selling by the end of the year. The others were giving excuses of no market for their products, but could not show evidence of these products. As a continuation of this project, training in bleach and disinfectant will be carried out for the more industrious PSG members.



The appropriate paper-based technology project started in August, and ended on 21st December 2018. The project trained 25 mothers to produce physiotherapy devices for their children using cardboard and paper.



The products were displayed at an exhibition organized on International Day of Persons with Disabilities (December 3rd) with the National Council on Persons with Disability (NCPD), and at the Accra Rehabilitation Centre on 20th December 2018. A Christmas party for the children at the La Pleasure Beach, marked the end of the APT project sponsored by EurHope..

Member Support Group:

The member support group met quarterly in 2018 and attendance improved considerably. Topics by resource persons included occupational therapy, the need for early diagnosis of neurological conditions, and how to choose an income generating activity.

NORTHERN REGION BRANCH

With support from the Local Development Fund (LDF) of Ghana Federation of Disability Organizations (GFD), Sharecare Ghana was able to establish and launch its Northern Region branch in July. Ibrahim Imoro was elected chair of the branch, Alhassan Abdul Somed Yussif, vice-chairman and Madam Feruza Napari women’s representative. The establishment of the regional branch makes Sharecare Ghana compliant with GFD’s requirement to qualify for membership.

NOGUCHI EXPLORATORY STUDY

A team from Sharecare Ghana met with the Director of the Noguchi Memorial Institute for Medical Research Professor Abraham Anang to discuss the exploratory study into autoimmune diseases carried out by NMIMR in collaboration with Sharecare Ghana in 2011, and propose a continuation of the research to better understand the disease condition. Senior staff of NMIMR Professor (Rt) Margaret Armar-Klemesu and Dr. Michael Ofori were present at this meeting. The NMIMR director promised to include this on the agenda in the coming year.



From Left: Dr. Michael Ofori, Prof. Armar-Klemesu and Prof. Anang of NMIMR Seated: Nana Yaa Agyeman and Christopher Agbega of Sharecare Ghana

MOBILE PHYSIO AND ADULT PHYSIO

Attendance at adult physio remained poor and there were fewer sessions during the year. The service will continue in the coming year.

Aviation Alliance Ltd. support for Mobile Physio however ended at the end of 2018 and Sharecare Ghana expressed its gratitude for the four year support. The support made it possible for needy families to access therapy services at the Sharecare Rehabilitation Centre and the hope is that this project can continue.

PARTNERSHIPS AND NETWORKING

GHANA FEDERATION OF DISABILITY ORGANIZATIONS

Sharecare Ghana participated in all activities of GFD including the Disability Network and the Career Fair 2018. On International Day of Persons with Disabilities (December 3rd), the disability movement presented a petition to the ministers of Gender, Children and Social Protection, Roads and Highways and Works and Housing on inclusion of accessibility features in all public infrastructure. The ministers promised to look at the petition.

SWEB FOUNDATION

Sharecare Ghana attended the SWEB Foundation partner organization (PO) heads conference in March and October 2018. With the imminent withdrawal of Liliane Foundation, a network of PO heads with the temporary acronym SPAID was formed. The SPAID charter and an MOU were signed by the PO head in October.

INTERNATIONAL ALLIANCE OF PATIENTS ORGANIZATIONS

Sharecare Ghana in collaboration with the International Alliance of Patients Organizations (IAPO) undertook an online survey from 23rd November to 3rd December in celebration of Patient Solidarity Day 2018. The 10 day online survey, published on Sharecare Ghana's Facebook page, shared via email and various WhatsApp platforms sought to understand the perception of the general public on autoimmune and neurological conditions as well as falsified and substandard drugs.

GHANA NON-COMMUNICABLE DISEASE ALLIANCE (GHNCDA)

Sharecare Ghana now a member of the Ghana non-communicable disease alliance (GhNCDA) took part in the GhNCDA high level meeting in August 2018 and the 'Our Views Our Voices' workshop in October 2018. Sharecare Ghana was selected as part of a working group to develop the GhNCDA advocacy document in December 2018.

2. FUNDRAISING & FINANCES

Investment

Investment with Liquide Consult yielded GH¢9,900 in 2018.

Dues

Membership dues paid through mobile money for the year amounted to Gh¢280 and the interest from MTN was Ghc12.88

Donations

EurHope donated Euros 5,000 (GhC26,500 for the APT Project; Ghanaman CRG Trust Fund donated GhC19,760 for training mothers of the Sharecare children in an income generating activity; SWEB Foundation donated GhC17,000 for community-based rehabilitation; and USAID through GFD donated GhC14,000 for implementation of the Sharecare Ghana strategic plan for one year. Aviation Alliance Ltd. donated GhC6,000 and indicated that their sponsorship was ending in 2018. IAPO donated \$250 (GhV\C1,145) for patient solidarity day 2018. We continued to receive monthly donations of GhC200 from Dr. Joyce Aryee. Sharecare Ghana is grateful for these sponsors and others who gave anonymously in cash and kind.

Finances

Total income for the year was Gh¢112,092.18 as against Gh¢60,005.83 the previous year and expenditure was Gh¢97,644.68 as against Gh¢73,387.05 the previous year. Investment of GhC30,000 in fixed deposit was rolled over. The detailed financial report is attached.

3. SHARECARE ESTABLISHMENT

Strategic Plan 2017 – 2022

An implementation plan of activities was developed for one year with the following objectives: To continue studies on autoimmune diseases started with Noguchi Memorial Institute for Medical Research; to enhance public knowledge, demystify and destigmatize the negative perceptions about autoimmune and neurological conditions; to advocate the setting up of assessment centres in all public polyclinics in Ghana; and to strengthen the organizational capacity and resource Sharecare Ghana to deliver on its core mandate.

By the end of the year, the engagement with NMIMR had reopened and they promised to put autoimmune disease research on the agenda; a new documentary film on Sharecare Ghana had been completed; government had been approached for adoption of the Sharecare Rehab Centre as the assessment centre for Osu Klottey District; and two Executive Council meetings had been held.

Executive Council

The Executive Council met twice in 2018 to review activities and financial reports; and approve plans and budgets for the year ahead. A final decision was taken for Sharecare Ghana to leave PAGE (Patients' Alliance of Ghana in Engagement) for non-performance, and handle patient solidarity day (PSD) activities.

Management and Staff

Management met weekly to review project implementation, and was supported by two national service personnel and interns from the University of Education, Winneba.

4. CHALLENGES AND LESSONS LEARNT

Sharecare Ghana has gone past its 10th year, which is an achievement – bringing autoimmune and neurological conditions to the minds of Ghanaians. However, Sharecare Ghana was unable to employ staff and meet the statutory obligations because of limited funds. The organization therefore had to rely on volunteers who were not always available. The newly established Northern Region branch is also without resources and is looking at the national secretariat for funding and direction.

Within the disability group, advocacy in the area of Sharecare Ghana's mandate was challenging because it was often drowned out by the better known and obvious disabilities. Sharecare Ghana found that more results could be achieved with a bigger constituency; hence continued membership with GFD, the SWEB PO's network and the Ghana NCD Alliance.

We restate that to make Sharecare Ghana sustainable, we have applied to the Ministry of Gender, Children and Social Protection through the National Council on Persons with Disability to adopt the Sharecare Rehabilitation Centre as the assessment centre for Osu Klottey in line with the Disability Law of Ghana and thereby give the centre accommodation. The centre would like to employ the social workers and physiotherapists who are currently only receiving allowances. Adequate funds would enable the centre to employ a speech therapist, but in the meantime, we have requested interns from the Department of Audiology, which has been approved.

Prepared by:
The Management Team
January 2019