



## SHARECARE GHANA 2010 ANNUAL REPORT



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	:	G 22,564
Social Welfare Reg. Number	:	DSW 3972
Registered Address	:	P.O. Box CT 4910 Cantonments Accra Ghana
Management Committee	:	Coordinator (Executive Director) – Nana Yaa Agyeman Secretary/Treasurer - Nana Konadu Agyeman
Executive Council (Member-Directors)	:	Doris Ahiney Obodai-Sai - Chairperson Suzy Ofosu Sylvia Amoako Adadzewa Otoo Nana Yaa Agyeman
Company Secretary	:	Egbert Faibille
Bankers	:	Barclays Bank Ghana Ltd
Auditors	:	Portfolio Financial & Management Systems
Advisors & Patrons	:	Prof. P.K. Nyame, Rector, Ghana College of Physicians and Surgeons – I think he is retired Dr. Albert Akpalu – Physician Specialist/ Neurologist, Korle Bu Teaching Hospital Dr. Nii Adjetey Bonney Andrews – Neurosurgeon, neuroGHANA Alhaji Abdul-Rahman Harruna Attah – Managing Editor, The Accra Mail.
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 COORDINATOR**

2010 was a bitter-sweet year for Sharecare Ghana. Owing to the generous support of our sponsors - ABANTU for Development, Ghana Federation of the Disabled/DANIDA, neuroGhana, Melting Moments and Alternative Source of Income Program (ASOIP) – we were able to carry out most of our planned activities. However, the loss of Naa Torshie Sai, a board director, and John Atta-Senya Jnr. is still painful to members. We wish them everlasting peace, and their families the understanding that they are finally without pain and at rest.

The deaths of these young people make it even more imperative that there should be research into autoimmune conditions in Ghana. Thankfully, the Noguchi Memorial Institute for Medical Research has promised that the long-awaited research will take off in 2011.

We would like to thank all those who volunteered their time for activities of Sharecare - members who attended meetings and functions at their own expense, and our loyal social workers and caregivers who are assisting our home-bound members and children with disabilities.

Activities during the year increased awareness among the general public of the existence and mission of Sharecare, leading to an increase in the number of enquiries and membership. The challenges, as usual, were the lack of a drop-in centre for members and a disability-friendly vehicle to do home visits and outreach programmes in other regions of the country. We are hopeful that these challenges will be overcome in the upcoming year when we get a permanent office.

Our heartfelt thanks go to our sponsors - ABANTU for Development, Ghana Federation of the Disabled/DANIDA, neuroGhana, Melting Moments, Alternative Source of Income Program (ASOIP) and all those that wanted to remain anonymous for supporting us to meet our mission. We look forward to further support from you and others who wish to help our cause.

In gratitude,

Nana Yaa Agyeman

# **REVIEW OF YEAR 2010**

## **Programmes Carried Out**

### **Outreach**

The year started with a seminar held in conjunction with the Ghana Association of Persons with Albinism, and sponsored by ABANTU for Development. The theme was the effect of Climate Change on human health, for persons with disabilities.

The seminar, which was held on World MS Day, was widely covered by both the electronic and print media. Copies of the presentations were made available to the National Council on Persons with Disability and to organizations of persons with disabilities (OPWDs) for them to disseminate them more widely.



Dr. Michael Ofori, Immunologist at the Noguchi Memorial Institute for Medical Research, making a presentation at the seminar

Members of OPWDs suggested that follow-up seminars should be organized with individual organizations so they can have more focus on their specific disabilities and be given ample time to ask questions.

### **Caregivers and Home-bound Members**

Sharecare Ghana, in collaboration with the School of Social Work at Osu, began an internship programme for students of the School to give home care to our home-bound members. The association paid the transport costs for this programme for a pilot phase of six months. This was made possible through the Flexfund Project initiated by the Ghana Federation of the Disabled and DANIDA.

This programme, though successful, is not financially sustainable. Sharecare therefore began advocating for the National Health Insurance Scheme to cover this all-important social service.

As part of this advocacy, we launched a handbook for caregivers from the perspective of the recipient as a guide to the students and to prod the State into carrying out a responsibility it is shirking.

Ms. Anna Bossman, Deputy Commissioner, Commission on Human Rights and Administrative Justice and Mr. Andrew Okaikoi, Chairman, National Council on Persons with Disability launched the handbook.



Home care gives chronically ill and severely disabled people the necessary assistance to become more independent, which is a basic human right. It also ensures the protection and safety of persons with disabilities in situations of risk – an obligation under the UN Convention on the Rights of Persons with Disabilities.

### **Sharecare Register**

Under the Flexfund Project, the organization started developing a database with a view to increasing membership. A register of existing members was compiled and radio and television announcements were made, inviting people with autoimmune and neurological conditions to join Sharecare Ghana. The response was however so low that the strategy was changed and the organization instead produced leaflets to educate people and encourage them to contact us.

Volunteers were also tasked to search for persons with neurological conditions (especially children). The search unearthed several children with obvious neurological disabilities who were being hidden in their homes. We could not just list their names and locations and leave. Some needed medical attention and we linked them up with medical doctors. We also gave them wheelchairs provided by the National Council on Persons with Disability.



**Naa Adjeley a 14-year old child can neither walk nor talk. She had never been assessed until Sharecare took her to see a physiotherapist who referred her to a neurologist.**

The organization took some of the children to the National Assessment Centre for children with cross-disabilities, hoping they would be referred to educational institutions or therapists.

Unfortunately, the centre could not help because it is in a state of neglect and lacks the facilities to carry out the necessary assessment. We involved the media to expose the shameful conditions of the National Assessment Centre and pressurize the Ministry of Education to revamp it. The news items were carried, but nothing was done about the centre.

### **Support groups**

The support groups continued to meet monthly for members to discuss the management of their conditions and other issues of concern to them.

The groups mourned the death of two members - Naa Torshie Sai, a board member and daughter of our chairperson, and John Atta-Senya Jnr. Representatives of the association attended both funerals.

The group in Accra invited the National Health Insurance Authority to make a presentation to it, as a follow-up to its petition in 2009 for health insurance to cover all disease areas, but they did not turn up, and subsequent efforts to get them failed.

Home visits to home-bound and ailing members continued. The number of members that could visit was limited however because of the lack of a disability-friendly vehicle.

## **Research**

Sharecare Ghana held discussions with the Noguchi Memorial Institute for Medical Research in 2008, with the expectation that a study into autoimmune diseases would be completed by the end of 2012. The cost of the study was estimated to be US\$657,812.50. Sharecare Ghana was able to raise only GHC6,000 (approximately US\$4,100). The Institute therefore re-wrote the research plan, and has given the assurance that a scaled-down study will start in 2011.

## **Operations and Staff**

The management team of two was able to continue working owing to the invaluable assistance of volunteers. Three more volunteers - social workers - joined Sharecare, bringing our number of volunteers to six. We were still without permanent office space and a drop-in centre for members but are trying to get this in the upcoming year.

## **Challenges**

One major challenge facing the association is the health of members. Many members are not in a position to attend meetings regularly or participate in scheduled activities. For this reason, the organization promotes partnerships with relevant institutions to enhance activities. Our partners in 2010 included the Ghana Association of Persons with Albinism, the School of Social Work, Osu, Accra, Ripples Health Care and of course all PWDs who patronize our activities.

The organization registered some members with the Livelihood Empowerment Against Poverty (LEAP) programme and tried to access the District Assembly Common Fund. This was also a challenge, because of administrative delays in the implementing government ministries.

## **Finances**

In 2010 the association received GHC17,514.99 in project funds, sponsorships and donations as against GHC4,734.49 in 2009. The detailed financial statement is attached.

Our donors and sponsors over the year included ABANTU for Development, GFD/DANIDA under the Flexfund, Alternative Source of Income Program (ASOIP) and a number of individuals. They have all helped stabilize and strengthen Sharecare and we owe them a debt of gratitude.

Our budget for the upcoming year is about GHC15,000, which we expect to raise through more innovative fundraising. About GHC9,000 will go towards therapy for six children

with neurological disabilities and the rest will be used for outreach programmes and office administration.

### **Goals for the Upcoming Year**

Sharecare Ghana is adopting Osu Alata in the Klottey-Korle District as the area of focus to support children with autoimmune and neurological diseases in 2011. Although the membership drive will be nationwide, we will actively seek children from deprived backgrounds in this designated area and finance their medical assessment and therapies. The rationale is that if other associations and societies do this, the whole country will eventually be assisted in this way.

In the initial phase, our aim is to raise funds for six children with neurological disabilities at an estimated cost of GHC9,000.

Another goal is to help our members find employment and income-generating activities. Care-giving for our home-bound members continues to be a priority since government social services are not performing adequately in this area. We will continue to raise funds for this and work out ways in which our home-bound members can earn money to pay for their upkeep. Although they have been registered on the LEAP programme, funds received by each member under this do not constitute a living wage, and need to be subsidized.

***Prepared By:***

***Name:*** Nana Yaa Agyeman  
*Coordinator*