



SHARECARE GHANA



2009 ANNUAL REPORT

OVERVIEW

Sharecare Ghana is an association of people with autoimmune and neurological conditions including their families and care-givers.

The association, founded in 2006, was registered with the Registrar General's Department in November 2007 as a non-profit organization and launched on June 19th, 2008. It is also registered with the Department of Social Welfare.

Charity Registration Number	:	G 22,564
Social Welfare Registration Number	:	DSW 3972
Registered Address	:	P.O. Box CT 4910 Cantonments Accra Ghana
Management Committee	:	The Management Committee was elected at the 1 st Annual General Meeting held on 10 th May 2008. Chairperson - Doris Ahiney Obodai-Sai Coordinator (Executive Director r) - Nana Yaa Agyeman Secretary/treasurer - Nana Konadu Agyeman
Executive Council (Member-Directors)	:	Doris Ahiney Obodai-Sai Naa Torshie Sai Suzy Ofosu Sylvia Amoako Adadzewa Otoo Nana Yaa Agyeman
Company Secretary	:	Egbert Faibille
Bankers	:	Barclays Bank Ghana Ltd
Auditor	:	Portfolio Financial & Management Systems
Advisors & Patrons	:	Prof. P.K. Nyame, Rector, Ghana College of Physicians and Surgeons. 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 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 subsequent disabilities.

REVIEW OF YEAR 2009

AWARENESS CREATION AND ADVOCACY

1. Greater Accra Region

Activities for the year began in February with a seminar on autoimmune and neurological diseases for persons with disabilities.

Participants were from the member organizations of the Ghana Federation of the Disabled, namely Ghana Association of the Blind, Ghana National Association of the Deaf, Ghana Society of the Physically Disabled, Parents' Association of Children with Intellectual Disabilities and Society of Albinos Ghana, as well as the Ghana Society for the Blind and Network of Journalists for the Promotion of the Rights of Persons with Disabilities in Africa.



Participants listening to Dr. Osei-Poku (r) with Dr. Kowornoo (seated by him)

It was funded by Globalfund for Women and ABANTU for Development, and the resource persons were Drs. Ida Kuwornoo and Osei Poku both of the Korle Bu Teaching Hospital in Accra.

2. Volta Region

Sharecare Ghana took on a volunteer as Volta regional representative to create awareness in the region of autoimmune and neurological disorders.

In August he met the chief and elders of Ashanti-Kpoeta in the Ho-West constituency of the Volta Region to educate them on the various diseases that fall under the classification of autoimmune and neurological conditions. The chief, Togbui Gadze VIII stated that the town has a population of about 11,200, and promised to pass the information on to them.

In October, there was an outreach mission to Amedzofe. Amedzofe is a mountainous town in Ho west with about 5,000 residents. The town has a teacher training college. The chief, Mr. Atikpui Akyemafoli VI, assembled the people to hear the objectives of Sharecare Ghana and was presented a write up on the organization.

3. Northern Region

The 51st annual general conference of the Ghana Medical Association took place in Tamale, the Northern regional capital, from November 4th to 9th, 2009 and Sharecare Ghana was given the opportunity to make a presentation to the doctors.

The GMA graciously gave free accommodation and participation in the conference. The presentation was a 10-minute documentary film highlighting 'autoimmunity' as a disease

specialty, and the need for referrals for early diagnosis. It was produced by members of the organization with information from the American Autoimmune-Related Diseases Association (AARDA).

The doctors received it well and noted the need to encourage medical students to specialize in immunology and rheumatology, in view of the symptoms that are often missed. They promised to include 'autoimmunity' in the scientific session of the next general conference.

Fifty doctors put their names on a contact list for Sharecare Ghana.

4. National Petition

The organization presented a petition to the National Health Insurance Authority and Parliament asking that the proposed amendment to the law establishing the National Health Insurance Scheme factor in all neuro-immunological diseases. This was followed with a letter to the Chairman of the Parliamentary Select Committee on Health. Both institutions are yet to respond formally.

SUPPORT GROUPS

The support group in Accra met monthly at the premises of neuroGhana kindly given at no cost to the organization.

Topics by guest speakers during the year included stress management, communicating with your doctor, drug management, alternative forms of treatment and nutrition. The group also met a representative of the Myasthenia Gravis Association of the United Kingdom.

Refreshments at the meetings were sponsored throughout the year by Melting Moments.

Support groups in the regions were unable to meet because of financial constraints on members.



**Mr. Charles Kodua of the UK
Myasthenia Gravis Association
(l) with Sharecare members**

RESEARCH

Fundraising for the Noguchi Memorial Institute for Medical Research/Sharecare Ghana study into autoimmune diseases started, but the project has been delayed because the target sum was not reached. So far GH¢6,000 has been donated towards the study and the money has been lodged in Noguchi's account. The project manager intends to scale down the project so that the amount raised can be used for a preliminary study.

NETWORKING AND MEMBERSHIP

Sharecare Ghana continued to participate in the activities of its umbrella and partner organizations.

Disability:

The National Day of the Disabled on June 23rd was observed with a press conference by the Ghana Federation of the Disabled (GFD), in which an appeal was made to the government to implement the provisions of the Disability Act of Ghana and ratify the UN Convention on the Rights of Persons with Disabilities.

International Day of the Disabled (IDD) was preceded by a week of activities including a mini trade fair, television and radio programmes and a national forum and awards ceremony on the day - December 3rd.

The Gender Committee of the GFD was inaugurated on July 10th to work towards empowering women with disabilities and enhancing their capacities. The Advocacy committee continued to draw up plans for promoting the rights of persons with disabilities.

The Disability Network comprising organizations working with and for PWDs and donor agencies met quarterly to discuss and synchronize the efforts of the various organizations involved in disability work.

Health:

The Greater Accra branch of the Coalition of NGOs in Health in Ghana met monthly and held an HIV/Aids anti-stigmatization workshop in August and health forum in December.

Social Welfare:

Sharecare contacted the School of Social Work at Osu in Accra which agreed to start a practical attachment programme for the students to give home care to severely disabled people in their communities. This programme, to start in 2010, will temporarily fill the vacuum in social service delivery whereby severely disabled people are left to their families or to manage on their own.

MEMBERSHIP

Following a programme on Metro TV in May, membership increased to 130 comprising people with various autoimmune and neurological conditions and care-givers. Some of the patients are still without a diagnosis even though they know that their symptoms are neurological. Membership is free, but members were encouraged to make donations whenever they could.

OPERATIONS/STAFF

Four members of the association volunteered to serve as representatives of their region. Francis Foli is the Volta Region representative, Harriett Atta Arkorful, Central Region, Agyei Nyarko, Ashanti Region and Aisha Haroun, the Upper West Region representative. Two interns, Nana Minkah and Kannie Chim, from universities in the United States worked with Sharecare Ghana in June and July. They did an excellent job attending meetings and workshops, planning the presentation to the Ghana Medical Association and researching social security benefits for persons with disabilities among other tasks.

With their departure the organization was left with eleven volunteers, only two of whom are full time. We hope to have new volunteers all over the country who can devote more time to the organization.

FINANCE

Fundraising continued to be a challenge because many companies said they were financially stressed. Donations received from individual in 2009 amounted to GH¢3610.00, as against GH¢8679.54 in 2008. The money was used for awareness creation and advocacy, while office expenses came from Sharecare's accounts. An amount of GH¢5,000 was used to purchase treasury bills to earn interest for office expenses. (Statement of Accounts attached) Fundraising efforts for research yielded GH¢6,000 which was paid directly into the account of Noguchi Memorial Institute for Medical Research.

FUTURE PLANS

1. Home care for persons with severe disabilities

The School of Social Work and Sharecare Ghana will draw up a proposal to raise funds for the students' internship programme. The programme is expected to take off by the second quarter of 2010.

2. Credit/Welfare Scheme

Several members of the organization, disabled in their adult years, are no longer able to do the work they were doing before. Some need financial assistance to re-establish a business, others need retraining, yet others can no longer work and need financial support to survive. The association will look at the possibility and work out the modalities for a Credit/Welfare Scheme for members.

3. Rehab unit

Plans to establish a rehabilitation unit and scholarship scheme are still on the drawing board. The plan includes a shop for products of independent living and health foods. To finance this project, the association is seeking donations and will intensify fund-raising efforts.

4. Fund-raising

A number of fund-raising activities have been planned for 2010 including a healthy foods cook fest and sponsored walk.

*Prepared by Nana Yaa Agyeman
Coordinator
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