



SHARECARE GHANA

2008 REPORT



Sharecare Ghana was established primarily to create awareness about the existence of autoimmune diseases and diseases of the central nervous system in Ghana and bring people with these conditions together. Sharecare's mission can be summed up as: Support, Awareness, Advocacy and Research.

Although the association was founded in 2006 and registered in November 2007, activities began in earnest in 2008.

Support group meetings

The first meeting of the support group took place in March 2008, and the meetings were held once a month after that, in line with Sharecare Ghana's quest to help members learn more about their conditions and how to better manage their lives.



Sharecare Ghana members at first meeting

At the inaugural meeting, officials from the Noguchi Memorial Institute for Medical Research attended to inform members of plans by the institute to research autoimmune conditions.

Other specialists that met the support group include officials from the Ministry of Health who spoke on re-generative health, an occupational therapist, who showed members how to adapt to disability and live independent lives, an emotional therapist and a clinical psychologist.

Some meetings were solely for members to share their feelings, experiences and ideas, and talk through problems facing them. The highlight of these was when a member shared with the group how a particular therapy had enabled her to stop using her two crutches and walk unaided.

Members said they found these exchanges useful in coping with chronic illness and disability.

Launch of Sharecare Ghana

The official launch of the association took place on June 19th in the form of a public lecture on autoimmune diseases and diseases of the central nervous system, at the Ghana College of Physicians and Surgeons, in Accra. Speakers were Drs. Albert Akpalu, Ida Kuwornoo, both of

Korle Bu Teaching Hospital and Michael Ofori of the Noguchi Memorial Institute for Medical Research.



Professor Paul Nyame, Rector of the Ghana College of Physicians & Surgeons and Chief Patron of Sharecare Ghana chaired the launch

Owing to the success of the launch, our chief patron, Prof. Paul Nyame, Rector of the college, recommended that we make it an annual event, which guarantees us the premises for free.

The Sharecare4u Endowment Fund for Research, Advocacy and Management was also launched that day.

Research by Noguchi

Sharecare Ghana, as a research and advocacy group is collaborating with the Noguchi Memorial Institute for Medical Research and other health institutions to research autoimmune diseases in Ghana. The project aims to establish the prevalence of autoimmune diseases and related disorders within the Ghanaian context.

The project proposal was completed in the last months of 2008 and a few copies sent to organizations to request funds to carry it out. The first phase of the project has a budget of GH¢66,750.

This study should generate information that will bring a better understanding of autoimmune-mediated conditions and hence their effective management.

Elections and staff

Elections were held during the year and the following were successful:

Dr. Doris Sai Chairperson

Nana Yaa Agyeman	Coordinator with functions of chief executive
Nana Konadu Agyeman	Secretary/Treasurer
Egbert Faibille	Company Secretary

The other structures remained the same.

Member-directors of the board: Doris Ahiney Obodai-Sai, Naa Torshie Sai, Suzy Oforu, Sylvia Amoako, Adadzewa Otoo and Nana Yaa Agyeman.

Chief Patron: Prof. P.K. Nyame, Rector, Ghana College of Physicians and Surgeons

Advisors/patrons: Dr. Albert Akpalu - Physician Specialist/Neurologist, Korle Bu Teaching Hospital, Dr. Nii Adjetey Bonney Andrews – Neurosurgeon, neuroGHANA and Alhaji Abdul-Rahman Harruna Attah – Managing Editor of The Accra Daily Mail.

Two Master of Philosophy (MPhil) students from the Department of Social Work, University of Ghana, were assigned as Graduate Interns at Sharecare Ghana to undertake their Concurrent Field Work Practicum. This was to train and equip them with practical social work skills, a requirement in partial fulfillment of their master's programme.

Sharecare found them useful and will encourage more of such internship programmes in the future.

Income and expenditure

Sharecare members do not pay dues, but over the year, we received GH¢8115.84 in donations and expended GH¢1629.34 on the launch, administrative costs and obligations to other organizations (details attached).

Membership and Networks

Sharecare Ghana was an active member of the Ghana Federation of the Disabled, attending meetings, workshops and the International Day of the Disabled.



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We also joined the Coalition of NGOs in Health in Ghana, the Transverse Myelitis Association based in the United States and the International Alliance of Patients' Organizations based in the United Kingdom.

The opportunity to network with and learn from all these organizations over the year proved invaluable.

International conferences

Sharecare attended two international events during the year - the 2008 Symposium on Rare Diseases in Seattle, Washington and the International Alliance of Patients' Organizations Workshop in Kampala, Uganda. Both events were educative and informative.

The Seattle symposium organized by the Transverse Myelitis Association, gave participants the opportunity to meet some of the top neurologists from Johns Hopkins University among others who gave presentations on management of pain, depression, sexual dysfunction, bladder dysfunction, spasticity and the many other symptoms that plague people with neurological conditions. The symposium also discussed self-advocacy and employment with disabilities. Details can be found at: <http://www.myelitis.org/rnds2008/index.htm> .

The Kampala workshop focused on patient-centred health-care and the advantages of networking when advocating for better health conditions. The report will be sent duly.

Immediate future plans

The Sharecare Ghana/Noguchi project should take off in 2009, and we will need to plan a series of activities to raise funds for the project.

We will continue to advocate that the health authorities treat autoimmune diseases with the seriousness deserved in the national health care delivery system. Autoimmune conditions are still not covered under the National Health Insurance Scheme in the country and perhaps the new Parliament will pay more attention to us.

**Prepared by Nana Yaa Agyeman
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