

EPILEPSY

Nobody has
a devil
inside them.



ANNUAL REPORT 2019 – 2020

MEDICAL ASSISTANCE SIERRA LEONE

supporting access to health care and
urgent medical treatment for communities
and individuals in Sierra Leone.



Medical Assistance
Sierra Leone

ACTION ON SPECIALIST CARE

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Medical Assistance Sierra Leone supports access to health care and urgent medical treatment for communities and individuals in Sierra Leone.

Working with local partners in the government health service and with a range of local NGOs, Medical Assistance Sierra Leone supports training for health workers, awareness-raising around health issues, and provides medication and equipment to under-resourced services.

1. INTRODUCTION

The arrival of COVID-19 in Sierra Leone has placed extra strain on a health system which was already experiencing huge capacity and resource-related issues. At the time of writing (March 2021), it is generally understood that COVID-19 is yet to reach its peak in Africa: “The best advice for Africa is to prepare for the worst and prepare today,” said WHO director-general Dr Tedros Adhanom Ghebreyesus.

We have sent pallets of sanitiser, masks and cleaning fluid to our clinic and NGO delivery partners. COVID has impacted on aspects of project delivery in a number of ways. It affected the size of public gatherings, resulted in the closure of schools and caused people to stay away from health services for fear of catching the virus. Our epilepsy awareness-raising activities took place with much smaller groups, often visiting households at a safe distance. The Epilepsy Support Workers also took on COVID awareness as part of their role, working with local health teams.

The focus of MASL continues to be on increasing the numbers of people accessing epilepsy treatment, and providing advocacy and support to those experiencing isolation and discrimination as a result of the condition. The project underwent an external evaluation in August 2020 which commended the work and

provided recommendations for the continuing expansion of project activities:

‘Behind the numbers we have seen a real and transformative impact on the lives of people with epilepsy through the cessation and reduction of seizures of those under treatment, the advocacy on behalf of patients and the increased overall awareness of accurate information enabling more people to access treatment and support’.

Dr Abdulai Dumbuya,
Abtech Solutions

This year we also developed our work further with the Sierra Leone Association of People With Albinism (SLAPWA), who share many of the same experiences of stigma and lack of appropriate health care that people with epilepsy experience. The report below details MASL activities from October 2019 to September 2020.

2. REACHING PEOPLE WITH EPILEPSY IN SIERRA LEONE

Our national programme working from three Epilepsy Hubs - Freetown, Kabala and Bo – continued to deliver awareness-raising and support, following government guidelines. Three Epilepsy Support Workers (ESWs) are based at each Hub, collaborating with health clinics, schools, places of worship and with community leaders – and bringing

MAFERE KEITA:

Forty Years of Uncontrolled Epilepsy Brought To An End

Mafere Keita, 54, a mother of three children was one person who accessed treatment this year as a result of the project’s awareness-raising activities. Mafere is a charcoal seller who had lived with epilepsy for over 40 years. She explained “*I travelled far and wide seeking help for my epilepsy from one traditional healer to another. I have gone through pains, molestation, violence as a result of my disability*” Mafere sobbed and showed the scars on her head.

“Last year my husband told the Chief Imam in our Mosque to drive me away and I was not to pray in the mosque any longer because I have had seizure twice in the mosque. I was suppressed by my husband and I had to leave the mosque and started to pray at home alone”.

Then one day Mafere was selling charcoal and a customer told her about the Epilepsy Association.

‘I went straight to the Epilepsy office to get more information and I was told to go for medication on Thursdays at the Connaught Hospital. It is over two years now I have not experienced any seizure as a result of the medication from the hospital’.

patients forward for treatment. The ESWs continue to pro-actively identify disabled people in the community who also have epilepsy and to help them to access the local clinics. Our collaboration with the Sierra Leone Autistic Society continues and we have supported their new Autism Inclusion Centre.



MASL Trustee Tolu Olaniyan delivered epilepsy awareness and training sessions for patients in three locations in October – Bo, Freetown and Kabala. The training focused

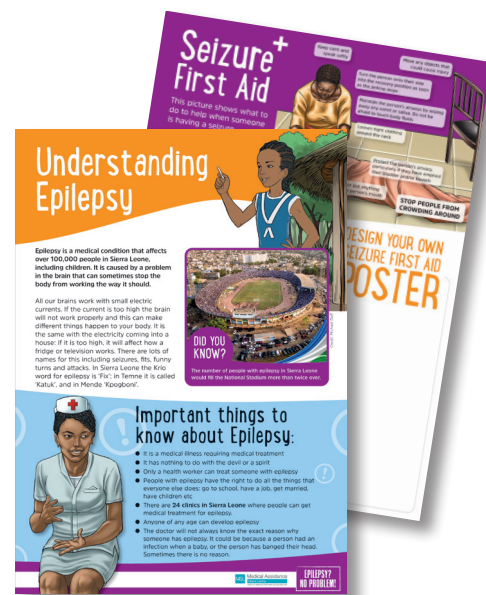
on 'Living Safely With Epilepsy' and was timed to coincide with Sudden Death in Epilepsy (SUDEP) awareness day. The emphasis was on reducing risks for patients with epilepsy, working towards improved patient outcomes. The patient forums were well attended, attracting 215 people in total. All sessions involved full patient participation; patients valued the opportunity to talk about all aspects of their condition. We are reminded time and time again that the profound stigma associated with epilepsy destroys self-esteem, relationships and families.

2.1 Raising Awareness and Reducing Stigma

This year we were able to complete the development of our primary school publication 'Jariatu Has Epilepsy'. Based on the journey to treatment of one of our patients in Freetown, the book tells a story of a young girl's alternative treatment and the intervention of an Aunt; at the back of the book there is a summary of key epilepsy messages and the Helpline number. Over 70,000 copies of the book were produced and shipped to Sierra Leone where they are being used at awareness-raising sessions.

An accompanying 4-page schools activity worksheet was also

developed. Both the book and the activity resource are available free of charge from our partners in Freetown. Other organisations working on epilepsy in Africa have expressed interest in using the resources and a Gambian version is in development.



Continuing our related work on witchcraft accusations and subsequent harmful treatment, Trustee Sarah Snow presented with Mary Penn-Timothy of the Sierra Leone Autistic Society at a two-day online forum on 'Witchcraft beliefs in the context of public health issues'. The aim of this work is to produce a toolkit for practitioners to help to demystify the common public health conditions associated with beliefs in witchcraft. The initiative was led by the University of Lancaster in the UK, the Witchcraft & Human Rights Network and the UN Independent Expert on Persons with Albinism.

2.2 Building Clinical Epilepsy Capacity

To date we have trained over 3,700 health workers across the country. Ongoing training ensures that new staff receive detailed epilepsy training and that other staff have refresher training, with the opportunity to share



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concerns and challenges. This year the project team delivered training for over 100 health workers in Makeni in February 2020, as well as the usual epilepsy modules at the School of Nursing in Freetown and at COMAHS, the medical school in Freetown.

For the clinical side of the work, we are focused on creating a community of well supported professionals with access to training and resources for themselves and patients. Dr Lisk and the clinical team plan to secure registration with the International League Against Epilepsy at the next Convention, which will result in a Sierra Leone Chapter of this global association of health care professionals and scientists working on epilepsy. This will create a supportive structure for the further development of clinical capacity-building which will also enable access to funds and further professional training opportunities with the ILAE, as well as opportunities to directly partner with MASL and other organisations. Dr Lisk, founder of the current clinical service and the country's only adult neurologist, is now retiring and a replacement will need to be trained. We are working closely with Dr Alusine Jalloh, Sierra Leone's first and only qualified Paediatric Neurologist, and are exploring opportunities for funded training in adult neurology for one of the health professionals involved in the epilepsy project.

We continue to benefit from significant quantities of free anti-epilepsy medication through our partnership with the US-based Row Foundation. This commitment involves the provision of Roweepra, a quality generic medication suitable for the vast majority of patients, including pregnant women. The other medication – five types – we fundraise for and purchase from the UK, with shipping every twelve weeks.

3 SUPPORTING PEOPLE WITH ALBINISM

We have been working with the Sierra Leone Association of Persons with Albinism this year as they raise awareness of their experiences of discrimination and stigma, and generate support for the specific health issues faced by Persons with Albinism. There are multiple local beliefs/myths surrounding the condition and very little support for the practical health problems faced by those with albinism.

Over 80% of people with albinism in Sierra Leone will die an early death from skin cancer. MASL has been supporting the medical costs of a mother with albinism who is receiving treatment for advanced skin cancer.

This year, after a fundraising drive around International Albinism Awareness Day in June, we were able to buy and send over 1000 bottles



of Altruist sunscreen to SLAPWA which were given out free of charge to Persons with Albinism. Our new partnership with sunscreen company Altruist Sun Screen means that we can now buy sun screen at greatly reduced

prices – just £1.20 per tube of high quality cream. This year we want to extend this support to include locally produced sun-protection hats and donated SPF 50 clothing which will be distributed at regional forums.

4 FUNDRAISING

We are very grateful to all those who have supported us this year with in-kind donations and fundraising. Over 11,000 people rely on the epilepsy medication that we purchase and ship to Sierra Leone. Apart from the donated medication from the Row Foundation, we do not have a grant for these costs and the funds are generated from individual donations, cake sales and through other creative methods. We would be very grateful for donations to support this essential expenditure. Like many organisations in the voluntary sector we have seen a decline in donations as a result of COVID.

We would love to hear from anyone who would like to run a marathon, hold a cake sale or organise a fundraising event for Medical Assistance Sierra Leone. We can help with publicity, materials and other support required.

Our sincere thanks to everyone who has supported our work this year.

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Medical Assistance
Sierra Leone

ACTION ON SPECIALIST CARE

Registered Charity Number: 1105330



Medical Assistance

Sierra Leone

Action on maternal & child health and specialist care

Receipts & Payments

Receipts

	1st Oct 2019 - 30 Sep 2020			2018-19
	Unrestricted £	Restricted £	Total £	£
Donations	6,108		6,108	1,061
Grants:				
Pro-Victimis Foundation		66,000	66,000	40,000
DFID		37,918	37,918	
ROW		1,460	1,460	
JRS		4,734	4,734	
Refunds		253	253	
Joffe Charitable Trust		0	0	15,000
Rhododendron Trust		0	0	1,000
Total receipts	6,108	110,365	116,473	57,061

Payments

Epilepsy Support		94,324	94,324	100,319
comprising:				
<i>Staff salaries in Sierra Leone</i>		36,245		38,340
<i>UK salary costs (financial & project mgmt)</i>		13,433		15,600
<i>Health worker training costs</i>		7,482		8,375
<i>other epilepsy support costs</i>		37,164		38,004
Fundraising & UK admin	876		876	2,116
Clinic costs & nurse sponsorship	106		106	10,143
Albinism Association Project	2,868		2,868	394
other costs	265		265	
Total Payments	4,114	94,324	98,438	112,972
Net of receipts/ (payments)	1,995	16,041	18,035	(55,911)
transfers between funds				
cash funds at last year end	524		524	56,435
cash funds at this year end	2,518	16,041	18,559	524

Statement of Assets & Liabilities at the end of the period

Cash funds			
Current account		18,559	524

Signature of Trustee

Print Name

SARAH SNOW

Independent examiner's report to the trustees of Medical Assistance Sierra Leone

I report on the accounts for the year ended 30th September 2020
Charity number 1105330

Respective responsibilities of trustees and examiner

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) and that an independent examination is needed.

It is my responsibility to:

- examine the accounts under section 145 of the 2011 Act
- to follow the procedures laid down in the general Directions given by the commission under section 145(5)(b) of the 2011 Act
- to state whether particular matters have come to my attention

Basis of independent examiner's report

My examination was carried out in accordance with the general Directions given by the Charity Commission.

An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the next statement.

Independent examiner's statement

In connection with my examination, no matter has come to my attention:

- (1) which gives me reasonable cause to believe that in any material respect the requirements:
 - to keep accounting records in accordance with section 130 of the 2011 Act and
 - to prepare accounts which accord with the accounting records and comply with the accounting requirements of the 2011 Act have not been met or

- (2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached



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Date: 28th July 2021