

# President's Message

A Stroke is a serious medical emergency, and strokes require immediate medical attention. We need education and awareness in Jamaica, so that individuals realize that the sooner a stroke patient receives care, the greater their chances of survival and recovery. A Stroke Center should be available in every parish with a trained Neurology team of doctors and nurses available to respond to stroke activation as soon as possible so that the impact of a stroke can be minimized.

The Center should also work with the local Emergency Medical Service to prepare for the arrival of potential stroke patients and fast track patients to a physician for immediate evaluation. Westmoreland has nothing even close to this.

It should be an exciting time for acute stroke treatment in Jamaica since there is the availability of clot busting drugs that can help to save more Jamaican lives, and help cut down on the high stroke disability rate in Jamaica. Thrombolytic therapy is the use of drugs to break up or dissolve blood clots, which are the main cause of both heart attacks and stroke. Research shows that giving thrombolytics within 3 hours of the first stroke symptoms can help limit stroke damage and disability.

The decision to give the drug would be based upon the results of:

- A brain CT scan to make sure there has not been any bleeding
- A physical exam that shows a significant stroke
- The patient's medical history

It is critical that a stroke victim immediately goes to the hospital when you first notice the warning signs of a stroke. The length of time between the first warning signs and the time you get to a hospital may be the difference between a good or poor outcome. Patients who present to the hospital within 3 hours of the first sign of a stroke may be able to receive the medication. Unfortunately, too many of our people are falling through this huge crack that we call the Healthcare System. So many never get there in time, and those who do have to sit and wait past the 3 hour window.

Our parish, Westmoreland has a woefully inadequate system to take care of our population of over 142,000 people. Without stroke awareness and education too many who have had a stroke shrug it off as something else, or as 'no big deal'...until paralysis sets in. Education and awareness is needed so that if Miss Mary has stroke symptoms she does not go and lay down hoping to feel better when she gets up, or she won't be forced to 'just drink some soup', because she now has problems swallowing.

Also Mr. Jones won't get up in the morning with his face twisted and look in the mirror and shrug it off thinking it's because he 'slept badly.' We want to get to the point where even children can recognize stroke symptoms and call 119. Hopefully the ambulance system is working in that community.

My mom lived in Westmoreland and she suffered a hemorrhagic stroke. As a nurse working in a technologically advanced hospital, that diagnose and treat patients with all different kinds of brain trauma, I realized that mom never received the level of care that was even considered negligible. Someone suggested taking some action because the lack of appropriate medical care was a travesty.

I agreed it was a travesty, considering that the doctor who saw mom NEVER ordered any brain imaging such as a CT or an MRI even though I could tell by just talking to her on the phone that he suffered a stroke. Also, when we did get a private doctor to order a CT of her brain which showed she did have a brain bleed and was sent immediately back to the hospital, she was told she did not require hospitalization.

We refused the legal action route, and opted instead for a campaign to educate, give awareness and support to stroke patients and their family of caregivers in the parish. Legal action would tie up our time and resources, and would not help the thousands of Westmoreland residents who still have no clue how to handle a stroke.

Specifically, because mom had a stroke in church and the symptoms went unrecognized, I know that stroke awareness is badly needed. Since stroke is the 3<sup>rd</sup> leading killer of Westmoreland residents, the 2<sup>nd</sup> leading killer of the males, and the leading killer of the female residents, something besides going to court is needed. Also the limited available data shows that middle aged women in Westmoreland as well as all over Jamaica, are dying at a higher rate from preventable strokes.

Milka Clarke Stroke Brain Trauma Foundation a charitable no-profit, founded to honor mom's memory, is based in Negril where mom died peacefully at home. We will provide stroke education, awareness, advocacy and support for residents of Westmoreland and adjoining areas.

We recognize that each 'patient' is an individual, first and foremost. Consequently, the treatment that patients receive must be specific to their individual needs. We plan to work collaboratively with the only Health Centre in Negril and plans are underway to have

discussions with the MoH, and other members of the Westmoreland Health Authority, so we can have a seamless operation, benefitting Westmoreland residents.

Since a stroke is a medical emergency, anyone who presents to an emergency room with symptoms of a stroke, should not have to sit and wait just like the person who has a broken arm. I have come to realize that sometimes money can't even help you in Jamaica...if you seek medical care from the public system. The medical system needs major improvement.

The Milka Clarke Stroke Brain Trauma Foundation envisions having a state of the art Stroke Brain Trauma Center located in the parish of Westmoreland. Negril or outlying areas adjacent to Negril would be ideal as Westmoreland has no NeuroPsych diagnostic equipment for stroke diagnosis, emergency treatment and support at the one Public General Hospital in the parish capital Savanna-La-Mar.

Our foundation's campaign, "Stroke is No Joke," is our theme beginning in 2015 and will highlight the greater impact of stroke on women in Westmoreland, including a disproportionate share of the caregiver burden. We are a young foundation, but we have a big vision of where we want to take stroke care in Westmoreland. Here are a list of some programs we hope to implement with the Westmoreland Health Authority's support.

Programs: Residents who participate in these programs will give consent to share data with the Health Centre, Hospital and other medical authorities.

# 1. Stroke Brain Trauma Registry

This registry will require voluntary registration for stroke victims and survivors, and will accept data for up to the previous ten years. Registrants will be asked to state the type of stroke. Community participants who sign up with the registry will provide information that will help develop a stroke data base for Westmoreland. This information will be shared with hospitals and will include high-risk participant screening results and contact information for the hospitals to use for follow-up. Hospitals can use this data to improve the quality of care, measure performance and support ongoing research into stroke prevention and care.

#### 2. Stroke Risk Identification Program:

Through this program we hope to conduct screenings that will help to identify individuals who are at high risk of stroke. Through this primary prevention program, with information gained through the Stroke Registry, health care professionals can review the screening outcomes with participants, counsel them on what interventions are needed to help prevent stroke, and give information on community medical resources for intervention treatment.

#### 3. Stroke Tele-Medicine Program:

Telemedicine Leads to Better Stroke Treatment Decisions. Rapid decision-making about treatment is critical in stroke patients, who can benefit greatly from appropriate treatment if it is administered within a narrow window of time. This can be hampered when patients are

being evaluated in hospitals in rural or underserved areas without a dedicated stroke team, such as in our local hospital in Westmoreland, or located too far away from practitioners with such expertise to rapidly treat a stroke patient, which is the case for most Jamaicans, especially those living in Westmoreland.

The audio/video tele-consultation system allows the stroke expert real-time visual and audio access to the patient, medical team and medical data at the remote site.

Video: <a href="https://www.youtube.com/watch?v=wVINH9-4lcc">https://www.youtube.com/watch?v=wVINH9-4lcc</a>

Web Info: <a href="http://www.calit2.net/newsroom/release.php?id=1345">http://www.calit2.net/newsroom/release.php?id=1345</a>

#### 4. Mobile Stroke Clinic

The Mobile Stroke Clinic would serve dual purposes. Naturally, several units would be needed. One set for emergency transport and treatment for transporting acute stroke cases to the stroke center/hospital. The other units would be used for the community mobile clinic outreach.

First, is to shorten the time between the onset of stroke-like symptoms and the delivery of "clot-busting" – or thrombolytic – drugs, which must be administered within three hours of when symptoms began or when the patient was last known to be well. The mobile stroke clinic

unit resembles an ambulance on the outside, but inside it contains highly specialized staff, equipment and medications strictly used for diagnosing and treating strokes.

The units will be equipped with a portable CT scanner that is capable of imaging the patient's brain to detect the type of stroke they are experiencing. The CT scans are wirelessly transmitted to the facility that the unit is connected to correspond with and neuro-radiologists, who deciphers if the patient is experiencing a stroke, and if so, whether the stroke is ischemic (caused by a blood clot) or hemorrhagic (caused by a ruptured blood vessel). Meanwhile, stroke neurologists access the patient's symptoms via telemedicine technology while en route to the hospital. This is our vision for stroke care in Jamaica.

A mobile lab like this, is able to test blood samples on board. If it is found that the patient is experiencing an ischemic stroke – which account for about 87 percent of all strokes – the onboard medical team can initiate intravenous (IV) tissue plasminogen activator (tPA) to attempt to break up the clot.

The key takeaway we want Westmoreland residents to know is when this program is up and running, to call 1-1-9 if they or a loved one is experiencing stroke-like symptoms, and the dispatchers will take it from there. Time is truly of the essence when it comes to stroke care, so the sooner a patient gets treatment, the higher the likelihood they will be able to receive the clot-busting treatment that could help them recover more fully, and live their lives without long-term disability.

It is important to know the symptoms of a stroke. Warning signs include sudden loss of speech, sudden loss of vision, weakness, dizziness or a severe headache, among many others. It is crucial to call 1-1-9 and get to the hospital immediately.

### 5. Access to Online Stroke Community for Stroke Caregivers

It is hoped that those who have online access will find that this service connects people from every stroke-related circumstance to find strength, practical tips, and even humor through the recovery process. Being a caregiver and/or family member of a stroke survivor can be isolating without a community offering strong support.

#### 6. Know Stroke Newsletter

This will be our official newsletter to be sent out via email service, at a timing interval yet to be decided. Since up to 80 percent of strokes are preventable, getting info into our communities and to encourage parishioners to accept screenings is a crucial step towards stroke prevention.

The newsletter will be offered free to all stroke survivors referred to the Foundation, and will ensure that it remains relevant and indispensable as a tool to guide and support all people with stroke and their families and caregivers through the difficulties and challenges that lie ahead for them. It will also help with the development of health promotion and stroke prevention services targeting the marginalized and the underserved, deep, rural areas of Westmoreland. We know that no matter the size of your hospital, you can create a stroke program as long as you have a person who is passionate about treating and preventing the condition.

# 7. Minutes Matter Program.

This campaign will educate people about the life-saving techniques of how to perform hands-only CPR, how to recognize a stroke (utilizing Act FAST), and the importance of early 119 activation. This program will incorporate our schools, churches, colleges, and businesses because there is a high level of apathy where stroke is concerned. The idea behind the campaign is meant to unite people, groups and organizations so we can come together during National Stroke Awareness month, the month of May, to promote stroke education.

# 8. Hospital to Home Program

We hope this post-stroke program will educate patients on secondary stroke prevention and on post-stroke issues. The program will provide a patient education manual and brochures. It will also include three-month follow-up interviews to stroke patients to help ensure improved care. Not only the patient, but his or her family and caregivers, as well, will benefit from this program of education and adaptation.

Hospital to Home includes follow-up to measure how effective the education was, allowing an opportunity for real quality improvement to better educate patients and families about stroke and how to avoid another one. This will require collaboration with the hospital and health centre.

### 9. Scholarship Program

We are pleased to announce four successful candidates for the inaugural Milka Clarke Self-Actualization & Academic Award Scholarship for the 2015-2016 academic year. This scholarship program is aimed at supporting young people of excellence with a proven financial difficulty at the Green Island High School, a school of Excellence in Hanover. I recently did a check and four of mom's six children called Green Island High School Home, several grandchildren also walked those hallowed halls, so it is fitting that the scholarship named after her resides there. That will be the home of the scholarship because mom was a huge advocate for education.

#### 10. Salt Awareness Week

During this week we hope to highlight activities which takes a positive and entertaining approach to highlighting the hidden salt content of processed foods. This week will be during Stroke Awareness Month and we will have a Blood Pressure Awareness Campaign. Jamaicans can cook well, so using so much salt is not necessary. Natural herbs and spices can do just as good a job of seasoning. We hope that these initiatives which are most important, help stroke management and limit strokes' capacity to kill too many people in Westmoreland.

# 11. Stroke Study Days

We hope this will be implemented where medical professionals can go for designated skills training in stroke management and care. We expect this to be coordinated with the Westmoreland Health Authority and other medical education professionals in the parish. This is expected to spread to other parishes, providing much needed opportunities for learning as well as sharing innovations and support.

# 12. State of the Art NeuroPsych Facility - (Stroke Brain Trauma Center)

The primary aim of this program will be to provide world class stroke treatment and support for residents of Westmoreland at very affordable rates. Since we are a non-profit foundation, the objective will be for providing care and keeping the facility functioning, not about making a profit. The use of the stroke Brain Trauma Center will most definitely not be exclusively for Westmoreland residents. However, they will never be denied timely treatment because of wealthy patients who can afford to pay.

We expect that the fee structure attached to services will have a schedule of fees for those who are assessed as being capable of paying. We do not want residents to expect a handout, but rather to pay what they can genuinely afford, so there is funding to maintain the necessary infrastructure and services required to diagnose and treat strokes:

- Computerized tomography (CT) scan
- Magnetic Resonance Imaging (MRI)
- Magnetic Resonance Angiography (MRA)
- (MRA) Doppler Sonography
- Radionuclide Angiography
- Transesophageal Echocardiography.

- Carotid Phono Angiography
- Electroencephalogram (EEG)
- ECHO Cardiogram
- CT Angiography (CTA)
- Carotid Duplex Scanning
- Acute Ischemic Response
- Acute Hemorrhagic Response
- Acute ICP Response
- Acute Vasospasm Treatment

These different imaging studies would be done at the Stroke Brain Trauma Center. Suffering patients would not have to travel almost one hundred miles to have any of them done.

Any treatment that is not specific to stroke diagnosis, treatment and rehabilitation care would attract a different fee schedule. It must be noted that stroke diagnosis, treatment, support and rehabilitation would be free and accessible to residents who are indigent, without reservations.

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This facility will be a nationally-recognized center that provides treatment and care for patients affected by strokes and other brain trauma through a scheduling system, except in cases of emergency. The Center will offer complete treatment beginning with emergency medical care required the instant a stroke occurs, to the short term and longer term rehabilitation and care required in the aftermath of a stroke.

At the Stroke Brain Trauma Center there will be an adequate range of healthcare providers from neurologists, neuro-interventional radiologists, radiologists, rehabilitation specialists, speech therapists, nurses, and psychologists working in multidisciplinary teams to create treatment plans specific to each individual. In addition, our specialists will tailor treatment for each patient based on their:

- Age, overall health and medical history
- Type of stroke or other brain trauma
- Severity of stroke/other brain trauma
- Location of stroke/other brain trauma
- Cause of stroke/other brain trauma
- Tolerance for specific medications, procedures or therapies
- Patient's opinion or preference

We envision that the Stroke Brain Trauma Center will offer medical and surgical options for every stage of stroke treatment and recovery. The Center's commitment will be responsive,

with flexible treatment and its attention to detail will make it exhaustive and offer stroke patients hope for optimal recovery and improved quality of life.

There is a whole list of other programs that we plan to bring forward in the future. We have just begun and our feet are just barely wet. According to the WHO data on non-communicable diseases, Jamaica, clearly does not have an operational policy, no action plan or strategy to help reduce the risk, incidence or complications of stroke. Something has to be done about that.

Our parish, Westmoreland is not a part of any stroke registry and also does not have adequate data to even help our foundation qualify our data with any degree of certainty, even though unofficially we know the degree of the burden placed on the society by stroke and the disability stroke survivors live with within communities.

#### 13. Stroke Rehabilitation

Rehabilitation is extremely important toward helping patients regain their independence following a stroke. That is why our Stroke Center will be so carefully assembled with a limited bed capacity for acute care and rehabilitation Care, to help patients achieve the best possible long-term outcomes and to make them feel whole again. Our stroke rehabilitation program will be recognized as a remarkable stroke specialty program for our focus on prevention, minimizing impairment, reducing activity limitation and maximizing patients' participation and quality of life.

Patients recovering from stroke may undergo:

- **Inpatient rehabilitation**: Patients are transferred to an acute patient rehabilitation unit for continued care so they may experience better recovery and regained function.
- **Outpatient rehabilitation**: Patients follow up with their physiatrist and may join a stroke support group to maximize stroke prevention.
- **Home-based rehabilitation:** Patients receive rehabilitation at home to help them return to family life, learn how to accommodate their homes for disability and regain strength and movement.

Stroke recovery doesn't end when patients leave the hospital. In fact, patients must make specific lifestyle changes to decrease the likelihood for the recurrence of stroke.

### 14. Speakers' Bureau

Individuals from the stroke registry who have the interest will be trained to educate men, women and children throughout the community about what it is like to live through and to live with a brain injury. The speakers will be taught to combine firsthand experience of living with a brain injury and general knowledge of statistical information to create and deliver highly inspiring, motivational and informative presentations.

Each speaker will have a unique, life-altering story that connects with all types of audiences. Because each speaker once lived without a brain injury, he or she will have the ability to connect with audiences.

Stroke Brain Trauma Awareness and Prevention are critical. To learn more about the Speaker's Bureau or to schedule a speaking engagement, please send us an **E-Mail** 

We aim to have our registry enrolled members complete the voluntary registry, so we can have solid documentation of case reporting, which will provide stroke brain trauma data going forward. We cannot accomplish this alone, so we will align ourselves with the medical community in Westmoreland, so we can at least have a collaborative effort to meet the following needs:

- 1. We are not political, but we need your support to lobby Government to get them to understand the impact of stroke on the people who vote.
- 1. Help us provide enough evidence based on data you provide, to get us support for our stroke awareness education and support services across the parish.
- 2. To make a case that there is a serious public health problem posed by stroke and stroke related disabilities.
- 3. Share with Public officials and medical policy makers how much stroke is impacting negatively on the people of Westmoreland and surrounding areas.
- 4. We are a non-profit foundation and will rely on your financial support to help generate enough income to keep programs accessible and available to all who need them. We know some people are really indigent, but those who can afford to, we are asking for your generous support towards defraying administrative costs, the website, database maintenance and other programs. Look at our giving options to see where your creativity can support our services to the community.
- 5. The facility project requires major funding but this is God's work and He takes care of what he orders. Funding is expected mainly from international sources but if you look at our donation page, you may get a few ideas of how to help us get to the place where Westmoreland is recognized throughout Jamaica and the Caribbean for its stroke care, stroke support, stroke advocacy, and stroke brain trauma rehabilitative services.

Feel free to contact me with any ideas or suggestions about MCSBTF matters.

Debbie M. Thomas-Brown Founder/President Milka Clarke Stroke Brain Trauma Foundation E-Mail

