



LUPUS FOUNDATION OF JAMAICA

PRESIDENT'S REPORT 2019

Dear Members and Friends

Much has changed in the world and for us in Jamaica since I first drafted this report much earlier in the year. As always in the wake of new challenges come new opportunities for innovation.

For those of us here at the Lupus Foundation of Jamaica (LFJ) this is more than a business meeting, it is an opportunity to re-connect - with each other, ("social distancing" notwithstanding) - and also with our core purpose, our core mission, our core values, as a community - the mission and values that unite us not just across the Island but over generations.

We continue a journey started in 1984 by a group of doctors, nurses and patients in a bid to intervene for the good of patients whose lives had been ravaged by the mysterious and often deadly disease and to change their lives for the better through access to treatment, information, support and advocacy.

Today, thirty-Five Years later, the people and the tools are different than they were. But we - donors, supporters, volunteers from all walks of life - continue to pull together in this unbroken and unrelenting effort, opening doors of hope for lupus patients across the island.

So in addition to reconnecting, it is also time for us to say thanks to you our members, volunteers and donors, for your invaluable support that helped make 2019 a year of many successes and real progress in the fight against lupus. During 2019 with God's help and your support we defied the many odds and achieved much for which to give thanks:

- Public Awareness campaigns for World Lupus Day and Lupus Awareness Month
- Partnering with National Health Fund to provide subsidized drugs to all Jamaicans with lupus through Individual Benefits Programme
- Securing Donations of Critical Diagnostic Equipment (Microscopes to Renal Pathology, Microplate Reader) to facilitate early diagnosis and interventions
- Restored full operation of the Lupus Learning Centre on 7 Barbados Avenue
- Centralized and strengthened our online and social media presence
- Launched a member platform through customer relationship management software
- Modernising our systems, both for people (Leadership structure, Volunteer training) and for operations – accounting software and procedures
- Updated Financial Records (4 years) and getting up to date with Companies Office
- Full Charity Registration with Department Of Cooperative And Friendly Societies Nov 29, 2020

A Foundation has been laid, and even in uncertain times, with your help we believe we can continue to meet the challenges - of expanding our reach and access through local support groups, community and corporate engagement and use of technology - while ensuring our sustainability by strengthening our funding streams, including donations and partnerships, income-generating programmes and skilled volunteers. I invite you to help us make this happen in 2020.

Desiree Tulloch-Reid
President



LUPUS FOUNDATION OF JAMAICA

Lupus Awareness

We made record impact in our goal of raising awareness about lupus and about the LFJ's programmes and services, with unprecedented reach through **print and electronic media** including 15 news features on lupus-related topics, 48 live media (TV and radio) appearances by LFJ representatives, and nearly 5000 direct engagements on **social media**, in addition to boots-on-the-ground community and corporate engagement.

We launched our **first Open House at the LFJ Learning Centre** and renewed signal events such as Laps for Lupus Awareness and our Annual Lupus Symposium attracting and engaging hundreds of participants including patients, public and health care practitioners.

The impact of government leaders including our Prime Minister and Minister of Health and Wellness speaking publicly about lupus and making a commitment to help was also unprecedented.

We are excited about the difference that greater awareness and understanding will make through earlier diagnosis and access to appropriate treatment, as well as improved understanding and quality of life for persons whose health is challenged by lupus.

Programmes and Services

During 2019 LFJ distributed over 5000 pieces of educational literature to health centres, physician's offices, workplaces, schools and individuals; We responded to over 400 visits, calls and messages seeking information and assistance - finding a treatment centre, accessing help for medical assistance, individual health counselling, connecting with a support network, and requests for print or video education and other resources from our Learning Centre. As of 2019 through Zoom link we have been able to accommodate live video/audio participation in our interactive Support Group meetings for our members outside of Kingston or unable to commute, with over 200 persons participating in support group meetings throughout the year, including our newly established Western Support Group.

Organisational Restructuring and Registered Charity Status

To more effectively respond to the growing demands and expectations, we successfully restructured the Organisation's leadership and operational framework to meet the highest international standards of governance, thus positioning ourselves for optimal impact and viability, while maintaining transparency, accessibility and accountability to our members and supporters across Jamaica and beyond.

After 30 years as a Registered Nonprofit Organisation, we crossed over into full status as a Registered Charity in accordance with the Charity Act of 2013, with the Organisation as well as our donors now enjoying the welcome tax relief associated with this status. We launched a new website, centralised our platforms for more coordinated communication, and modernised our systems for member access and engagement.

Membership

New member enrolment and existing membership renewal is at record numbers with the launch of electronic member sign-up and sign in page and an interactive member portal through customer relationship management software, with over 300 active members at the end of the year. Volunteers have worked hard to clean, update and format our database to keep abreast with our



LUPUS FOUNDATION OF JAMAICA

growing membership across the Island. We were pleased to welcome the emergence of the dynamic Western Support Group, who have greatly strengthened our impact across the Island, providing lupus patients and their families in the West long-needed access to a support network and raising awareness through several local community efforts.

Lupus Added to the National Health Fund Individual Benefits Programme

Our engagement with government policy makers and implementers saw a major breakthrough with the much-welcomed addition of lupus to the National Health Fund's Individual Benefit's programme. This has provided access, in many cases for the first time, to state-of-the-art treatments through substantial subsidies to hundreds of patients struggling with the high cost of medications.

Donors and Sponsors

We have been very blessed to have enjoyed the support of several corporate as well as community organisations and Individuals who have supported our efforts through their own events and initiatives. Special thanks to Sagicor Foundation (2019 Sigma Run Foundation), First Dance Studios (Jesus Christ Superstar Musical), Mr Kevin Wilson (diagnostic equipment for Kidney Biopsy to UWI), Loving Arms Jamaica (Lupus Awareness Campaigns May and October), Go Run Running Club (Break of Dawn Charity Run/Walk) and Shortwood Teachers College (Annual Health Fair) for all the planning, effort and good will that went into executing these events for the benefit of lupus patients.

We also thank other generous donors of cash or kind including Dr Harry Nyanteh, Guardian Life Foundation, MDRT Foundation, FLOW Foundation as well as all the individuals who supported our own fundraising campaigns and events. Special thanks to our (veteran and new) partner Businesses and Organisations participating in our Can drive and Member Discount Programme. We look forward to a growing number of sustaining donors of all sizes in this coming year as we seek to improve convenience through a donate button soon to be set up on our website.

Volunteers

Finally, we wish to thank our tireless volunteers who have stuck with us on this journey, giving their time, skills, effort and love to the cause and to the persons we serve. This Organisation continues to be volunteer-run, from our Directors and Board Members who lead or serve on our Programmes, Finance, Services and Development Committees, to the volunteers on the ground, sustaining our Support Groups, manning the Help line, reaching out with visits and calls, mobilising help, writing and publishing or sharing their stories. Special thanks to our volunteer health professionals who continue to empower individuals and families with the knowledge and skills to survive and thrive as lupus warriors.

Plans for 2020

We are excited about the possibilities and plans for the coming year: We are looking forward to a strengthened Executive Board with the skills and commitment to take the organisation to greater and wider impact. In the near term, we are seeking to increase our cadre of skilled volunteers and gifts of support in the areas of Communications and Marketing, Design, Project Management, Development, Writing, Publishing, Accounting and Finance, and various Health Care fields. We also aim to extend our reach and impact through continued expansion of our membership in all parishes, better assess local needs and resources, establishing and sustaining support more Groups across the island including identifying and training leaders and forming strategic partnerships with local health



LUPUS FOUNDATION OF JAMAICA

care and other organisations. We would like to promote more local research to better understand our needs and influence/advocate for appropriate and effective allocation of resources to the fight against lupus in Jamaica.

To accomplish this we need a lot of resources including funding, on a consistent and predictable basis, and we need your help. We are seeking to launch new income-generation projects and to strengthen existing ones and we need the expanded support of our members and friends in the task of keeping us viable. Consider becoming a sustaining donor, fundraiser or volunteer today. Please get in touch with us at info@lupusfoundationjamaica.org or visit our website <https://lupusfoundationofjamaica.wildapricot.org/Support> .

Let's Fight Lupus Together!

With much appreciation

Desiree Tulloch-Reid