**TITLE: Educational Priorities for Primary Care Providers on Systemic Lupus**

**Erythematosus in the Caribbean**

Supplemental Table 1: Generated Ideas on what Primary Care Physicians should know about systemic lupus erythematosus in the Caribbean

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| Diagnosis – common features and signs | Familiar with specific clinical symptoms and signs:1. Dermatological: Heterogeneity of lupus rashes (malar and more), photosensitivity, alopecia, mucocutaneous ulcers in darker skin tones
2. Musculoskeletal: inflammatory arthritis, Jaccoud’s arthropathy, myositis
3. Systemic symptoms: fever, weight loss, fatigue
4. Serositis and how this may present clinically (pleural or pericardial involvement differentiated from costochondritis)
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| Aware of available basic laboratory measures of organ involvement and chronic inflammation (not reliant on specialized tests)1. On full blood count: Low white blood cells (more neutropenia than lymphopenia); low hemoglobin – normocytic, chronic disease pattern; hemolytic anemia; reactive thrombocytosis – acute phase reactant; or thrombocytopenia [immune mediated, antiphospholipid antibody syndrome (APS)]
2. Prolonged PTT or false positive VDRL (consider APS)
3. On metabolic panel - hypoalbuminemia – suspect kidney involvement and/or chronic inflammation
4. Elevated inflammatory markers (ESR, CRP)
5. Urinalysis/Urine protein:creatinine ratio – proteinuria and hematuria – suspect kidney involvement
 |
| 1. Knowledge of SLE classification criteria and differentiated from diagnostic criteria
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| Key causes of lupus morbidity and mortality | 1. Aware of silent kidney disease and evaluate for this at time of diagnosis
2. Aware that chest pain in lupus can be catastrophic: serositis, acute coronary syndrome (high risk cardiovascular disease in SLE), myocarditis, thromboembolic disease
3. Aware of vascular emergencies (cerebrovascular accidents, pulmonary embolism and secondary APS)
4. Aware of SLE psychosis
5. Aware of infection as leading cause of death in SLE
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| Common Comorbidities in Lupus | 1. Awareness of common comorbidities (diabetes mellitus, hypertension, osteoporosis, thyroid disease) that may be associated with lupus including high risk of cardiovascular, cerebrovascular and metabolic disease
2. Know when and how to screen for comorbid disease - Routine lipid panel, glycated hemoglobin (HbA1c), bone density scan
3. Know to perform electrocardiogram (EKG), chest x-ray, echocardiogram in patients with respiratory or cardiac symptoms
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| Assessment for and management of lupus flares | Awareness that Lupus is characterized by flares which can present with new organ involvement1. Know how to monitor for new disease activity
2. Assess symptoms and signs at each visit for flare of disease
3. Assess basic labs: metabolic panel, blood counts, urinalysis, dsDNA, complement levels, UA, Urine protein:creatinine ratio, PT/PTT
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| Medication Management | 1. Be aware of medications used to manage acute lupus flares and to maintain disease control in lupus
2. Know that hydroxychloroquine is as a foundational component for all treatment regimens in SLE
3. Know that there are a variety of therapies to treat SLE
4. Know how to use corticosteroids and overarching principle of using the lowest dose necessary to avoid high dose and prolonged steroid use
5. Be aware of complications of medications used in lupus
6. Know that Infection is the #1 cause of mortality in SLE in the Caribbean)
7. Understand the importance of medication monitoring for cytopenia, renal and liver disease (medications should only be used when monitoring is available)
8. Know of potential for HCQ toxicity and the need for ocular screening at baseline and 5 years, then annual screening
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| Non-pharmacological management and lifestyle interventions | Sun protection1. Know to recommend UVA/B protection – SPF 30+ daily sunscreen and other (floppy hats, reflective clothing)

Nutrition1. Educate patients on which foods and/or supplements to avoid - alfalfa sprouts, echinacea
2. Know importance of healthy eating (low saturated fats and cholesterol, low sugar, less processed) and aware of anti-inflammatory diet (Mediterranean diet advised)

Regular exercise1. Educate patients on importance of weight-bearing exercise, muscle strengthening, aerobic exercise, balance

Lifestyle1. Know to educate patients on avoiding substance use (tobacco, marijuana, alcohol)
2. Emphasize the importance of maintaining ideal weight
3. Emphasize the importance of sleep hygiene and address stress management
4. Understand the value of patient support groups
5. Encourage participation in a self-management program online if not available locally

Cardiovascular risk management1. Maintain normal blood pressure
2. Know the importance of lipid/cholesterol control and use of statins as needed
3. Know to refer high risk patients for cardiac stress testing when ischemic heart disease is suspected – low threshold for referral

Metabolic health risk management1. Know to control of blood glucose
2. Encourage a calcium rich diet (preferred) or calcium supplements, Vitamin D3
3. Check level of 25OH vit D and supplement accordingly (goal vitamin D level of 30 – 50 ng/ml)

Infection risk management1. Avoid over-use of steroids
2. Educate patients on measures of infectious disease control - hand sanitizer, masks as needed
3. Encourage vaccinations for influenza, covid, pneumonia, shingles and human papilloma virus

Reproductive health management1. Know contraceptive options recommended in SLE and APS
2. Understand the increased risk of human papilloma virus/cervical cancer in SLE patients
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| Pregnancy in SLE | Recognize importance of family planning in SLE Patients1. Understand that preconception planning is a must!
2. Know and use the HOP-STEP\* discussion aid
3. Know that pregnancy has the best outcomes when SLE disease is controlled and to avoid pregnancy until in remission for at least 6 months
4. Optimize medications for safety during pregnancy
5. Know the importance of the high-risk obstetric clinic
6. Understand that lupus patients are at higher risk for disease flares in the antepartum and postpartum period
7. Aware of pregnancy morbidity and mortality, especially in patients with active SLE - Miscarriage, Preterm labor, Preeclampsia, neonatal lupus
8. Understand medications in pregnancy – which medications are safe to use (eg. can continue hydroxychloroquine)
9. Aware of implications for patients with SSA/SSB and/or APL antibodies

Reproductive health education1. Know which medications are teratogenic and counsel patients on avoidance of pregnancy
2. Encourage the use of Birth control (hormonal) for all patients on teratogenic agents
3. Know that fetal echocardiogram is needed in SSA/SSB + mothers (16-26 weeks)
4. Check for proteinuria, incident lupus nephritis and monitor lupus disease activity markers (dsDNA, Complement levels) in pregnancy
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| Specialist Referral | Should Initiate1. Early referral to Rheumatologist if available locally or through CAR
2. Early referral to Cardiology if associated cardiovascular disease
3. Early referral to Nephrology if there is renal involvement (proteinuria or decreased GFR)
4. Referral to high-risk Obstetrician for pregnancy counseling
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| Clinical Trials | 1. Know and understand the types of clinical trials in SLE
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| Telemedicine | 1. Be educated on opportunities for tele-rheumatology
2. Be educated on telemedicine etiquette in rheumatic diseases – what can or cannot be treated remotely, when is an in person visit advised
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Supplemental Table 2

Participant Description

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| --- | --- | --- |
|  | RheumatologistsN (%) | Non-Rheumatologists N (%) |
| N =13 | 9 | 4 |
| Sex |  |  |
| Female | 8 (88) | 4 (100) |
| Age [Mean(SD)] | 42.4 (8.2) |  |
|  |  |  |
| Nationality |  |  |
| Caribbean | 8 (88) | 4(100) |
| Non-Caribbean | 1 (11) | 0 |
| Geographic Location |  |  |
| \*Caribbean based | 5 (55) | 2 (50) |
| US based | 3 (33) | 2 (50) |
| UK based | 1 (11) | 0 |
| Years of Experience |  |  |
| <5 years | 0 | 2 (50) |
| 5-10 years | 3(33) | 1 (25) |
| >10 years | 6 (67)) | 1 (25) |
| Academic affiliation |  |  |
| Yes | 4 (44) | 3 (75) |
| No | 5 (55) | 1 (25) |

\*Caribbean islands represented: Bahamas, Barbados, Jamaica, Saint Lucia, Trinidad and Tobago, US Virgin Islands

Supplemental Table 3: Final List of ideas for voting

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| **Primary Care Providers Should…** |
| **Diagnosis and Clinical Acumen** |
| 1 | Know the specific dermatologic manifestations |
| 2 | Know and recognize inflammatory arthritis and arthralgia in SLE |
| 3 | Know that SLE is a systemic disease and recognize symptoms of SLE |
| 4 | Know how SLE serositis may present clinically |
| 5 | Know the common hematological manifestations of SLE |
| 6 | Aware of role of coagulation profile in assessment for antiphospholipid syndrome (APS) in SLE |
| 7 | Be aware of implications for VDRL testing (false positive VDRL in APS) |
| 8 | Recognize features of inflammation and SLE organ system involvement on the metabolic panel |
| 9 | Be aware of appropriate use of inflammation markers |
| 10 | Know the importance of urine tests in screening for kidney involvement |
| 11 | Understand the importance of monitoring complement levels |
| 12 | Understand the role of the antibody panel in SLE diagnosis and implications for specific antibodies (ANA, dsDNA, Smith)] |
| 13 | Know the lupus classification criteria (any) |
| 14 | Know about the risk of silent kidney disease and evaluate for this at time of diagnosis] |
| 15 | Be aware that chest pain in lupus can be catastrophic |
| 16 | Be aware of potential vascular emergencies in SLE (CVA, PE, APS)] |
| 17 | Be aware of SLE psychosis and its presentations |
| 18 | Be aware of infection as leading cause of death in SLE in the Caribbean |
| 19 | Know of the most common comorbidities (DM, Osteoporosis, CVD, Thyroid) ] |
| 20 | Know to screen for common comorbidities - BP monitoring, Routine lipids, HbA1c, dexa scan |
| 21 | Know to perform EKG, CXR, Echocardiogram in symptomatic patients |
| 22 | Know how to monitor for new SLE disease activity |
| 23 | Know to assess for specific clinical symptoms (eg. Foamy urine) and signs (eg. leg edema) at each visit to screen for new flare |
| 24 | Know to complete certain standard blood and urine tests at each visit to monitor for flares |
| 25 | Understand that there may be an inflammatory myositis in lupus |
| 26 | Know that SLE can present with new organ involvement |
| **Management Strategies** |
| 27 | Know of the importance of antimalarials (hydroxychloroquine) in SLE therapy |
| 28 | Know that there are multiple therapies available for the treatment of SLE |
| 29 | Understand appropriate use of corticosteroids in SLE  |
| 30 | Understands that higher risk of infection is a consequence of SLE medications |
| 31 | Know to monitor SLE medications to screen for medication adverse effects (such as cytopenia, renal and liver complications)  |
| 32 | Be aware of ocular toxicity of antimalarials and know how to give this medication and screen for eye involvement |
| 33 | Know the role of UV rays in exacerbating lupus and can counsel patients appropriately about UVA/B protection |
| 34 | Know which supplements and foods patients should avoid and counsels appropriately (can cause SLE flare or interact with medications) |
| 35 | Know to educate patients on a healthy/anti-inflammatory diet |
| 36 | Know to educate patients about the role of exercise |
| 37 | Counsel patients on avoiding substance abuse in the setting of SLE and SLE treatment, including tobacco, marijuana, alcohol use |
| 38 | Know to educate patients on importance of maintaining ideal weight |
| 39 | Understand the importance of sleep hygiene and stress management, and counsel patients appropriately |
| 40 | Aware of role of self-management programs and local support organizations for patients with SLE |
| 41 | Know importance of maintaining normal blood pressure <130/80 and plays close attention to hypertension management |
| 42 | Understand the importance of Lipid control and use of statins as needed |
| 43 | Know to refer patients for cardiac evaluation - Stress test for high-risk patients when ischemic heart disease is suspected |
| 44 | Understand the importance of blood glucose control in the setting of SLE and when using corticosteroids |
| 45 | Know the importance of and can counsel patients on Calcium and Vitamin D supplementation |
| 46 | Understand the implications of corticosteroid use and avoidance of over-use of corticosteroids |
| 47 | Know to educate patient on ways to prevent infection - hand sanitizer, masks as needed |
| 48 | Know the importance of vaccinations in infection prevention in SLE - flu, pneumonia, hpv |
| 49 | Know the contraceptive options recommended for SLE including APLS |
| 50 | Know of the Increased risk of HPV infection and cervical cancer in SLE patients |
| 51 | Ensure an early referral to Rheumatologist if available locally or through the Caribbean Association for Rheumatology |
| 52 | Know to refer patients early for specialist consultation as indicated based on symptoms – eg. nephrology, cardiology  |
| 53 | Know to refer patients to a high-risk Obstetrician for pregnancy counselling |
| 54 | Should be aware of opportunities for clinical trials in SLE |
| 55 | Know about current opportunities for tele-rheumatology |
| 56 | Know how to manage SLE medications in the setting of infection, illness or other adverse event |
| **Management of Reproductive Health** |
| 57 | Know that Pre-pregnancy planning is critical  |
| 58 | Know that lupus remission for at least 6 months is critical prior to considering pregnancy |
| 59 | Know which medications to continue or hold during pregnancy |
| 60 | Know to involve high risk Obstetrician in care of pregnant lupus patient and in planning for pregnancy |
| 61 | Know of high risk for SLE disease flares in the peripartum period |
| 62 | Know of pregnancy related morbidity and mortality in SLE for patients and infants |
| 63 | Be aware of pregnancy complications related to presence of SSA/SSB or APL antibodies |
| 64 | Understand that some SLE medications or teratogenic and patients should be on contraception while on these therapies |
| 65 | Know about and uses the HOP-STEP discussion aid |
| 66 | Know to check for proteinuria and hematuria during pregnancy and the implications fo positive tests |