Educational Tools for Childhood Lupus

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Objectives

- **Understand challenges** that may hinder providers from educating childhood lupus patients and caregivers
- **Identify patient education resources** to improve health literacy and self-management
- **Demonstrate how these resources may be used** in everyday practice
Use Lupus Foundation of America Educational Tools for Childhood Lupus

- **Read and Understand** the tools provided in this training found on the [National Resource Center on Lupus](#).
- **Share** the tools with staff and patients.
- **Post** tools clinic bulletin boards. Save in charts!
- **Reach out** and ask Lupus Foundation of America Health Educators for more information.
Prevalence of Childhood Lupus

- 15-20% of SLE diagnosed in childhood with greater Lupus Nephritis prevalence among childhood SLE (A)
- SLEDAI score in childhood SLE > adult SLE at diagnosis (A)
- The disease is more active, with more serious outcomes when diagnosed in children (A)
- Average age of diagnosis with childhood SLE is 12-14 (B)
  - Mostly after 8 years of age
  - Very rare before age 5
  - Girls more than boys 8:1
SLICC Diagnosing Criteria
Systemic Lupus Erythematosus International Collaborating Clinics (SLICC)

- SLICC is an international research group est. in 2008
- SLICC Criteria: Provides criteria useful in diagnosis of SLE. Criteria needed: at least 4 (at least 1 clinical and 1 immunological) or Lupus nephritis (in presence of ANA or anti-dsDNA)

### Clinical Criteria

<table>
<thead>
<tr>
<th>Clinical Criteria</th>
<th>Immunological Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Acute cutaneous lupus</td>
<td>1. ANA above laboratory reference range</td>
</tr>
<tr>
<td>2. Chronic cutaneous lupus</td>
<td>2. Anti-dsDNA &gt; laboratory reference range, ELISA: twice above laboratory reference range</td>
</tr>
<tr>
<td>3. Oral ulcers</td>
<td>3. Anti-SM</td>
</tr>
<tr>
<td>4. Non-scarring alopecia</td>
<td>4. Antiphospholipid antibody</td>
</tr>
<tr>
<td>5. Synovitis</td>
<td>5. Low complement</td>
</tr>
</tbody>
</table>

### SLICC Diagnosing Criteria

- 1. Acute cutaneous lupus
- 2. Chronic cutaneous lupus
- 3. Oral ulcers
- 4. Non-scarring alopecia
- 5. Synovitis
- 6. Serositis
- 7. Renal
- 8. Neurological
- 9. Hemolytic anemia
- 10. Leukopenia (<4000/mmc3 at least once)
- 11. Thrombocytopenia (<100,000/mmc3 at least once)

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#### Seen & Unseen

**Symptoms of Childhood lupus**

**Seen**

- CNS effects
- Lupus Nephritis
- Fatigue and Malaise
- Arthritis like joints
- Hair loss
- Skin rashes
- Cardiopulmonary
- Gastrointestinal

**Unseen**

- Depression and Anxiety [E]
- Financial burden
- Unable to do “it all” or sometimes even “some of it”
- Limited safe treatment options
- Uncertain future
- Isolating
- Pain
5 Challenges of Lupus Education

<table>
<thead>
<tr>
<th>Provider</th>
<th>Parent</th>
<th>Patient (child)</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1 Lupus is heterogeneous</td>
<td></td>
<td></td>
</tr>
<tr>
<td>#2 Organizing Chronic Illness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>#3 Family Dynamics and Varied Learning Needs</td>
<td></td>
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<tr>
<td>#4 Access to care</td>
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<td></td>
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<tr>
<td>#5 Academics and School/Childhood Lupus and the Future</td>
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</tbody>
</table>
Challenge #1: Lupus is Heterogeneous

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<thead>
<tr>
<th>Provider</th>
<th>Parent</th>
<th>Patient (child)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No one size fits all diagnosis, disease process or treatment.</td>
<td>So... how can we predict its course of disease in child? Lots of questions.</td>
<td>“I don’t know anyone with lupus.”</td>
</tr>
</tbody>
</table>

No 1 Question searched on National Resource Center on Lupus is:

“What is Lupus?”

1. Teach patient to access Lupus.org and 2. National Resource Center on Lupus at Resources.lupus.org. 3. And provide Health Educator information.

“40-80% of the medical information patients are told during office visits is forgotten immediately, and nearly half of the information retained is incorrect.” (G)
Tool-
Symptom tracker

- Help your child to use a symptom tracker

Have parents review at home with child patient. Follow with open-ended questions

Role play at home:
Have child practice discussing symptoms using this tracker. Encourage them to initiate use of tracker every 4 weeks.
Tool-Coping Strategies

- Learn about and establish healthy coping strategies early to start good habits

  - Ask open-ended questions
  - Ask them to identify if their coping strategies are healthy or unhealthy
  - Allow them to try to identify alternate coping strategies if they have unhealthy ones
  - Encourage options

https://resources.lupus.org/entry/coping-with-lupus-guide
Tools for Getting Emotional Support

Children state that they don’t know other people with lupus. Help them connect with a support system:

- Family, Friends
  - resources.lupus.org/entry/10-things-to-tell-your-friends-about-lupus
- Others with Lupus
  - Articles or blogs
  - resources.lupus.org/entry/teens-adjust-to-life-with-lupus
- Local Support group via Local LFA chapter or hospital/clinic
  - http://www.lupus.org/chapters
- Online support at:
  - lupusconnect.inspire.com

Challenge #2: Organizing Chronic Illness

<table>
<thead>
<tr>
<th>Provider</th>
<th>Parent</th>
<th>Patient (child)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short office visit time.</td>
<td>Making hard choices.</td>
<td>Not prepared mentally? Would rather be doing something else?</td>
</tr>
<tr>
<td>Care coordination.</td>
<td>A lot to juggle.</td>
<td></td>
</tr>
<tr>
<td>Distractions.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Hospitalizations are almost inevitable with childhood lupus. We know mean LOS for a study was 5.9 days. And for every 2 patients with childhood lupus, there was at least one hospitalization each year.(K)

Tools for Medication tracker, Lupus Care tracker, Lupus Flare Plans
Tools — Medication Tracker

- Before visit:
  - For Provider – do you have a care coordinator, social worker or navigator?
  - Encourage forwarding medical documents, lab results, discharge paperwork.
  - For Clinic Staff –
    Encourage all office staff
to become familiar with medications commonly used for lupus:
  
- During visit:
  - For Provider – Review during visit
  - For Patient – Tell in own words their meds they take and why they take

Tools — Care Tracker

- During visit:
  - For Provider – Print out and Review during visit, encourage note taking
  - For Patient – Keep a copy in wallet, in personal files, at school if needed

**Tool – Lupus Flare Plan**

- **During visit:**
  - **For Provider** – Print out and Review during visit, encourage note taking
  - **For Patient/child** – Write the words they want to use to communicate about their lupus symptoms (i.e. “angry red rash,” “itchy pain,” “bubble joints”)


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**Challenge #3: Family Dynamics and Varied Learning needs**

<table>
<thead>
<tr>
<th>Provider</th>
<th>Parent</th>
<th>Patient (child)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who to provide education to?</td>
<td>Cultural Barriers, Religious Barriers, Parenting preferences</td>
<td>Age and level of understanding is varied</td>
</tr>
<tr>
<td>Who shows up?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Direct communication between provider and child, builds trust and the child’s desire to make good health choices.*

- **Listen and meet kid at their level, challenge them. Can you discuss topics with parents before needed in clinic?**
  - [https://resources.lupus.org/entry/organizations-that-offer-support-and-resources-to-caregivers](https://resources.lupus.org/entry/organizations-that-offer-support-and-resources-to-caregivers)
  - Other caregiver toolkits
  - LupusConnect

- **Take on new tasks, slowly take on more tasks in care and lead questions**
Q1. True or False:
As a provider, it is important to listen to your patient, allow for choice and support their individualized point of view.

TRUE

Q2. True or False:
Patients have better adherence and health outcomes when provider-patient communication is positive.

TRUE

Q3. True or False:
Doctor’s interrupt patients every 23 seconds.

TRUE
How we *should* communicate about health with patients who are children?

Understand Barriers & Propose Tasks

- Find out what barriers there might be to different aspects of lupus treatment or care
- Consider the patient’s readiness for discussion of serious topics
  - Are there cultural or religious challenges?
  - Are there learning challenges?
- Provide clear instructions. Use teach back method.
- Consider rewards or incentives for healthy habits or self-management behaviors.
If risk is not imminent, propose a schedule for learning. Prepare them for the hard conversations that need to be had because of lupus. Consider including parents with objections to education in this plan.

- Bone health
- Reproductive Health
- Serious signs and symptoms and risk of complications
  - Heart problems, clots
  - Lupus Nephritis risk is increased for children

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**Ways Providers Can Engage Child Patient Self-Management and Care**

**JANUARY**
- Talk about Healthy bones
  - [Link](https://resources.lupus.org/entry/monitoring-bone-health-in-children-and-teens-taking-corticosteroids)

**FEBRUARY**
- Talk about medical management
  - [Link](https://resources.lupus.org/entry/medications-used-to-treat-lupus)

**MARCH**
- Talk about sex
  - [Link](https://resources.lupus.org/entry/sexual-health-and-reproductive-issues)

**APRIL**
- Talk about sun exposure
  - [Link](https://resources.lupus.org/entry/5-need-to-know-facts-about-sun-safety)
Tool – Caregiver Toolkit

- Before visit:
  - Caregiver to read through toolkit
  - Gather necessary documents, make copies, file away

- During visit:
  - Provider to ask caregiver if any questions.
  - Does their insurance have education services to help?
  - Does job have EAP?
  - Would they benefit from counseling services?

Provide Health Educator information:
1.800.558.0121

Challenge #4: Access to Care

<table>
<thead>
<tr>
<th>Provider</th>
<th>Parent</th>
<th>Patient (child)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inconsistent attendance makes it hard to maintain treatments</td>
<td>Transportation Insurance/No insurance</td>
<td>Transportation Insurance/No insurance</td>
</tr>
<tr>
<td></td>
<td>Disability</td>
<td>Disability</td>
</tr>
<tr>
<td></td>
<td>Can’t take off work</td>
<td>Can’t take off work</td>
</tr>
<tr>
<td></td>
<td>Missing school</td>
<td>Missing school</td>
</tr>
</tbody>
</table>

#1 Reasons constituent reach out to Health Educators is for support because they need resources for financial, medical, mental health, transportation.

Are there programs in place for transportation. Social Workers, Navigators, Care Coordinators, local support groups?

Discussions together on insurance, referrals, etc. Can call health educator for additional support or resources.
resources.lupus.org/entry/financing-your-medical-care

https://resources.lupus.org/entry/social-security-disability-ssi-benefits
## Challenge #5: Academics and School/Childhood Lupus and the Future

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<thead>
<tr>
<th>Provider</th>
<th>Parent</th>
<th>Patient (child)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need to instill self-management skills to transition to adulthood</td>
<td>Desire to assist in getting child through to adulthood and maximize options.</td>
<td>Quality of Life, impact of disease and Academic performance Issues</td>
</tr>
</tbody>
</table>

*The higher the disease activity, the more “inferior academic performance in children with lupus”.*

- Educate family on the resources available. Help by framing their expectations for current and future school/work.
- Put a 504 plan in place
- Encourage communication with school nurse and admin

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### Lupus in Life Resource – **School 504 plan**

- An Individualized Healthcare Plan (IHP) is a written plan the school nurse develops for children with health care needs that require special services from the school (like administering medications).
- An Emergency Care Plan (ECP) should be developed by the school nurse to ensure that the correct actions are taken if your child has a lupus flare or other lupus-related medical emergency at school.
- A 504 plan is a set of accommodations that allow children with disabilities fair access to the same general education program as their peers. Children with any disability qualify for a 504 plan.
- An Individualized Education Program (IEP) is a more stringent plan for children who need a specialized education due to learning disabilities caused by their condition. A child must undergo an Independent Educational Evaluation (IEE), paid for by the school, to determine if he or she qualifies for an IEP.

[resources.lupus.org/entry/communicating-with-your-childs-school](resources.lupus.org/entry/communicating-with-your-childs-school)
Lupus in Life Resource – School

resources.lupus.org/entry/school-survival-for-kids

Tools for School

Build your Child’s school care team
www.resources.lupus.org/entry/a-guide-to-lupus-and-school#school02

- Clear communication with school is important.

- Lupus Health Checklist for School
College Ready? Career Ready?

1. Find Rheumatologist in your college city
2. Arrange a way to get your RX if you’re away from your home provider
3. Update your Emergency Contact Card
4. Complete HIPAA Authorization form
5. Know warning signs for lupus complications
6. Know triggers
7. Decide who you want to tell about your lupus on campus
8. Think: How can 1st year schedule be manageable? Start slowly.
9. Register with student accessibility office
10. Know where to get emotional support

https://resources.lupus.org/entry/top-10-action-items-for-college-bound-teens-with-lupus

Reminder: Transition Tips!

- ACR Guidelines:
  http://www.gottransition.org/researchpolicy/index.cfm
- Remember to ask “Koala Baby Front or Koala Baby Back” and get your child patient’s input.
- Engage with the child to improve their interest in their own health, speak directly to the child even early on.
- Give them tasks that are small and then build up from there.
- Get the connected with others and provide them with our resources that they can revisit as needed.
Encourage progression of self-management tasks

<table>
<thead>
<tr>
<th>CHILD PATIENT</th>
<th>PARENT</th>
<th>PROVIDER</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>EASY</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Checks into appt. Provides Name, DOB, reason for visit</td>
<td>• Assures Child seated next to provider to encourage direct conversation</td>
<td>• Build Rapport</td>
</tr>
<tr>
<td>• Recalls allergies to MA/Nurse</td>
<td>• • Listen</td>
<td>• Understand barriers</td>
</tr>
<tr>
<td><strong>MODERATE</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Has list of providers, medicines</td>
<td>• Encourage and allow kids &gt;12 years old to have one on one time with provider</td>
<td>• Encourage child to recall baseline health and new symptoms</td>
</tr>
<tr>
<td>• Makes refill calls, lab result calls</td>
<td>• • Assist in finding Rheum at college</td>
<td>• • Encourage child to initiate important topics</td>
</tr>
<tr>
<td><strong>ADVANCED</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Consider options for insurance for adulthood</td>
<td>• Set up appointments and attend with child</td>
<td>• • Listen to questions outside scheduled conversations</td>
</tr>
<tr>
<td>• Schedule own appointments with home providers</td>
<td>•</td>
<td></td>
</tr>
</tbody>
</table>

Thank you!!!

Contact Lupus Foundation of America for more information:

1.800.558.0121
References/Resources


C. Mental Health Issues in Children and Teens with Lupus, Knight, Andrea, MD, MSCE. https://resources.lupus.org/entry/mental-health-in-children


References/Resources

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I. https://resources.lupus.org/entry/academic-performance-in-children
