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

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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.

Note on How to Read Slides

Indicates an opportunity to instill self-management skills

Indicates an opportunity to encourage planning (homework/prep-work)

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 *https://sliccgroup.org/*
- **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		Immunological Criteria
1. Acute cutaneous lupus	7. Renal	1. ANA above laboratory reference range
2. Chronic cutaneous lupus	8. Neurological	2. Anti-dsDNA > laboratory reference range, ELISA: twice above laboratory reference range
3. Oral ulcers	9. Hemolytic anemia	3. Anti-SM
4. Nonscarring alopecia	10. Leukopenia (<4000/mm3 at least once)	4. Antiphospholipid antibody
5. Synovitis	11. Thrombocytopenia (<100,000/mm3 at least once)	5. Low complement
6. Serositis		6. Direct Coombs test in absence of hemolytic anemia

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

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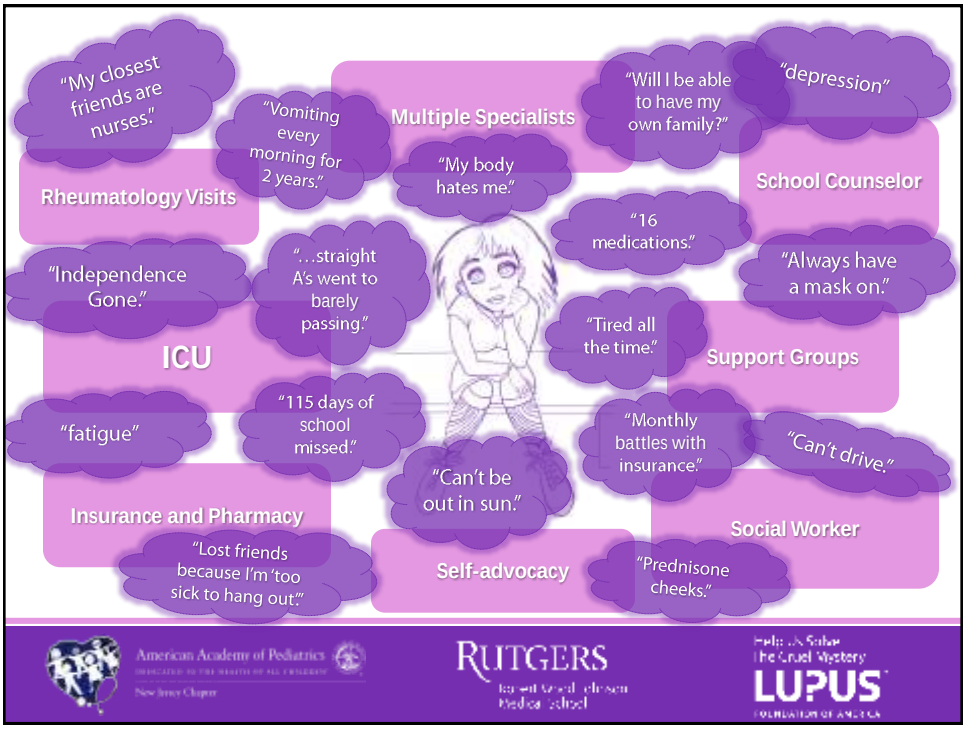

5 Challenges of Lupus Education

Provider	Parent	Patient (child)
#1 Lupus is heterogeneous		
#2 Organizing Chronic Illness		
#3 Family Dynamics and Varied Learning Needs		
#4 Access to care		
#5 Academics and School/Childhood Lupus and the Future		

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Challenge #1: Lupus is Heterogeneous

Provider	Parent	Patient (child)
No one size fits all diagnosis, disease process or treatment.	So… how can we predict its course of disease in child? Lots of questions.	"I don't know anyone with lupus."

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.

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"**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)

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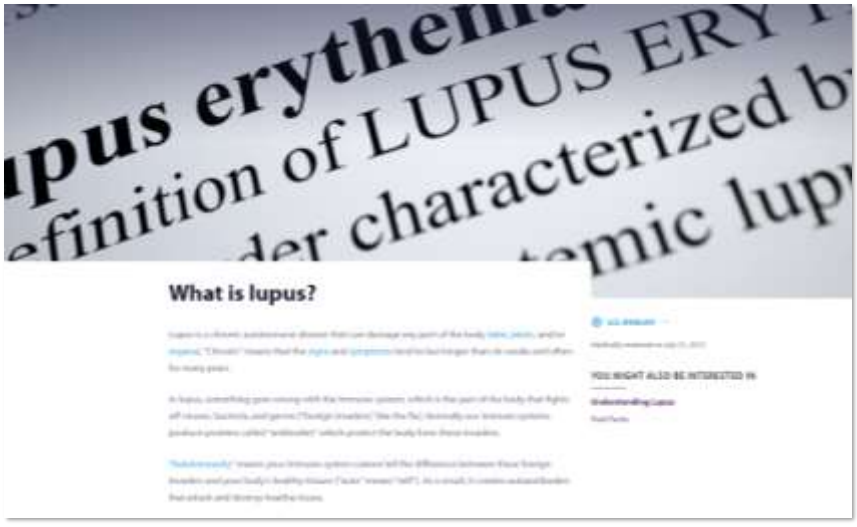
National Resource Center on Lupus

resources.lupus.org



https://resources.lupus.org/entry/what-is-lupus

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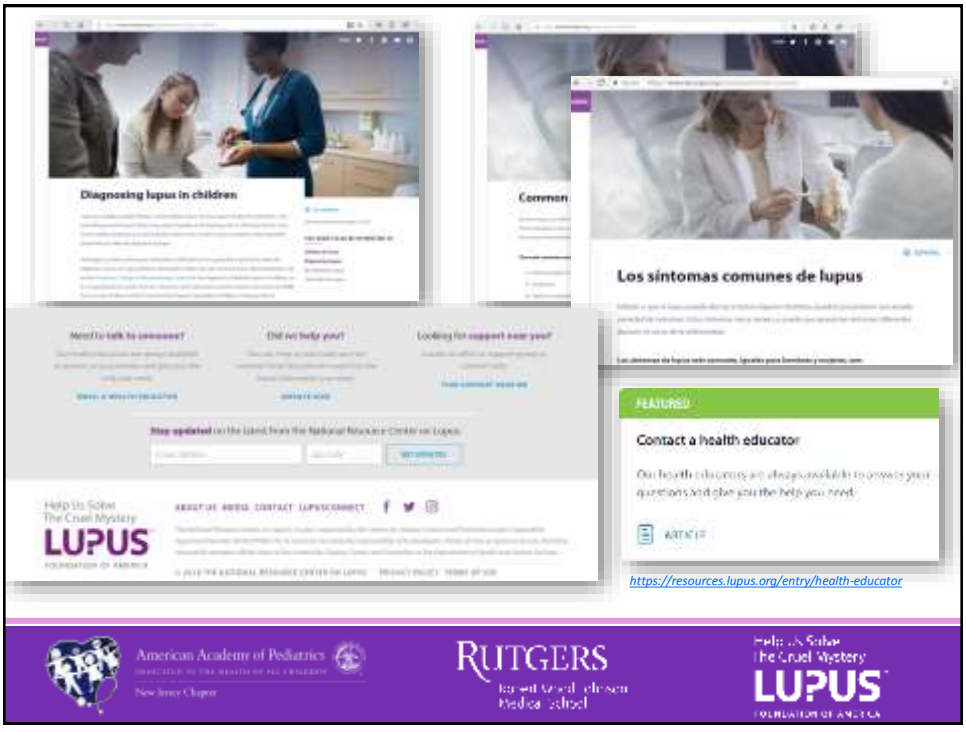

https://resources.lupus.org/entry/health-educator

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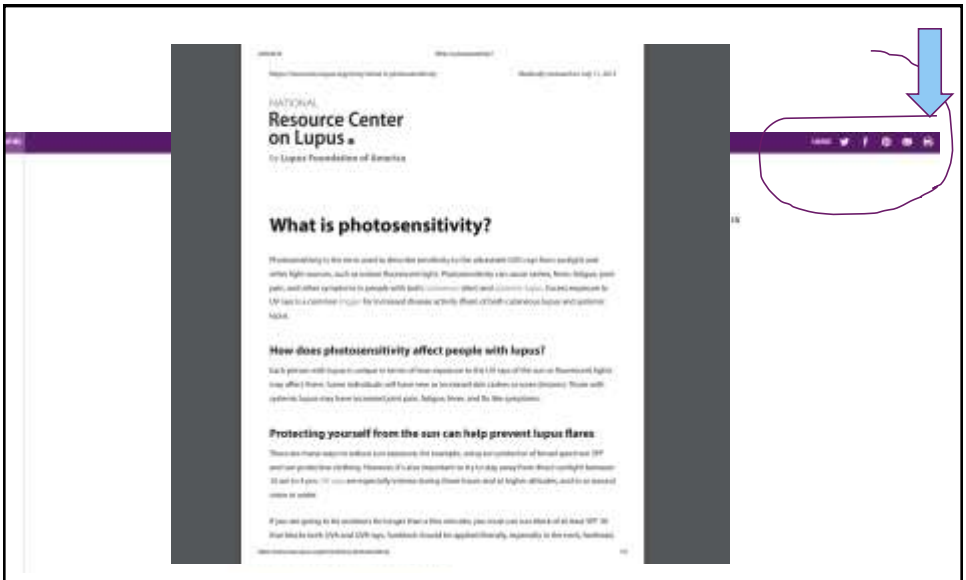

https://resources.lupus.org/entry/what-is-photosensitivity

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https://resources.lupus.org/entry/how-to-explain-your-childs-lupus-to-others

https://resources.lupus.org/entry/teaching-children-and-teens-about-their-lupus

Tool-
Symptom tracker

- **Help your child to use a symptom tracker**

encourage planning

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

self-management skills

Role play at home:

Have child practice discussing symptoms using this tracker.

Encourage them to initiate use of tracker every 4 weeks.

https://s3.amazonaws.com/lupusorgnrcl/PDF-documents/LupusImpactTracker.pdf?mtime=20160913143409

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

COPING WITH LUPUS

What's In Your Coping Toolbox?

LUPUS

Instructions: An important part of learning to live with lupus is figuring out which coping strategies work best for you. Whether it's a skill you already have or a new tool you want to try, your goal is to choose strategies that help keep you well, overcome difficult situations, and maintain a fulfilling life.

Coping strategies are the tools, skills, and behaviors you use to adjust to challenges and deal with difficult situations.

If you've been newly diagnosed with lupus, you may experience challenges with:

- Understanding lupus and how it can affect the body
- Accepting your diagnosis and dealing with your emotions
- Identifying and managing your symptoms
- Understanding and sticking with your treatment plan
- Getting the most out of your medical appointments
- Finding resources and support

This worksheet will help you reflect on the tools, strategies, and skills that have worked for you in the past, those you might want to try, and those that have been recommended by your health care team. Examples are provided to help you get started.

STEP 1: LIST COPING STRATEGIES THAT HAVE WORKED FOR YOU IN THE PAST (NOTE IF IT HELPED YOU ADDRESS A PHYSICAL OR EMOTIONAL CHALLENGE)

EXAMPLES

ADD YOUR RESPONSE HERE

Journaling

Therapy / counseling

Taking a break

Asking for help

https://resources.lupus.org/entry/coping-with-lupus-guide

https://s3.amazonaws.com/lupusorgnrcl/PDF-documents/Developing_your_coping_toolkit.pdf?mtime=20180117143512

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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

Provider	Parent	Patient (child)
Short office visit time. Care coordination. Distractions.	Making hard choices. A lot to juggle.	Not prepared mentally? Would rather be doing something else?

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:*

  https://resources.lupus.org/entry/medications-used-to-treat-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

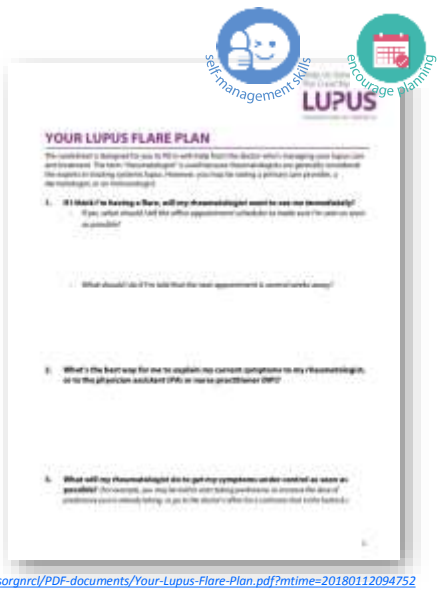
https://s3.amazonaws.com/lupusorgnrcl/PDF-documents/Medication-and-care-tracker.pdf?mtime=20180112131023

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")



https://s3.amazonaws.com/lupusorgnrcl/PDF-documents/Your-Lupus-Flare-Plan.pdf?mtime=20180112094752

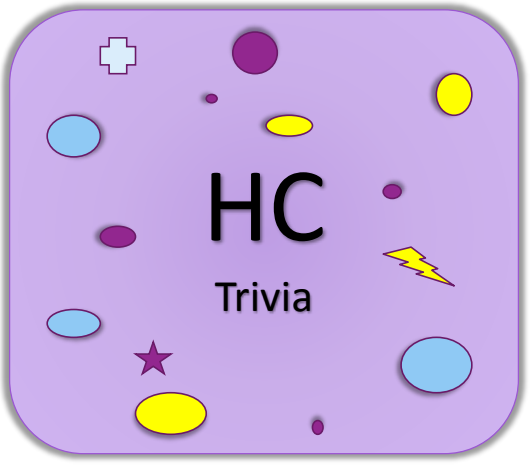
Challenge #3: Family Dynamics and Varied Learning needs

Provider	Parent	Patient (child)
Who to provide education to? Who shows up?	Cultural Barriers, Religious Barriers, Parenting preferences	Age and level of understanding is varied

Direct communication between provider and child, builds trust and the child's desire to make good health choices(H).

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 **Other caregiver toolkits LupusConnect**	**Take on new tasks, slowly take on more tasks in care and lead questions**

Health Communication Trivia



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

self-management skills

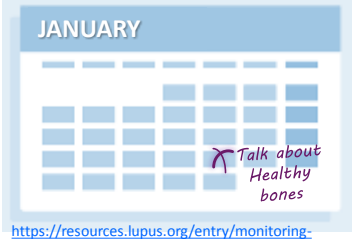
- Find out what barriers there might be to different aspects of lupus treatment or care
- Consider the patient's readiness for discussion of serious topics
  - *Are there cultural or religious challenges?*
  - *Are there learning challenges?*
- Provide clear instructions. Use teach back method.
- Consider rewards or incentives for healthy habits or self-management behaviors.

Ways Providers Can Engage Child Patient Self-Management and Care

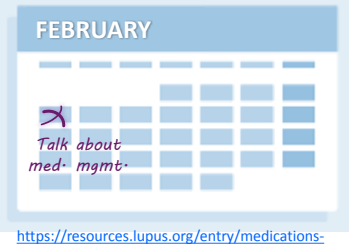
encourage planning

- 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

encourage planning



https://resources.lupus.org/entry/monitoring-bone-health-in-children-and-teens-taking-corticosteroids



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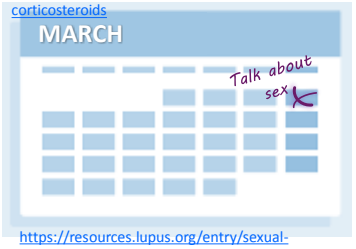
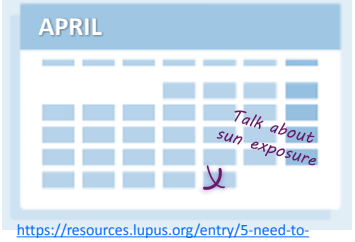


https://resources.lupus.org/entry/sexual-health-and-reproductive-issues



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*

https://s3.amazonaws.com/lupusorgnrcl/PDF-documents/FINAL-LFA-Caregiver-Toolkit.pdf?mtime=20170404144311

Challenge #4: Access to Care

Provider	Parent	Patient (child)
Inconsistent attendance makes it hard to maintain treatments	Transportation Insurance/No insurance Disability Can't take off work	Transportation Insurance/No insurance Missing school

#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

Provider	Parent	Patient (child)
Need to instill self-management skills to transition to adulthood	Desire to assist in getting child through to adulthood and maximize options.	Quality of Life, impact of disease and Academic performance Issues

The higher the disease activity, the more "inferior academic performance in children with lupus(i)."

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**

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

encourage planning

resources.lupus.org/entry/communicating-with-your-childs-school

- 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.

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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.

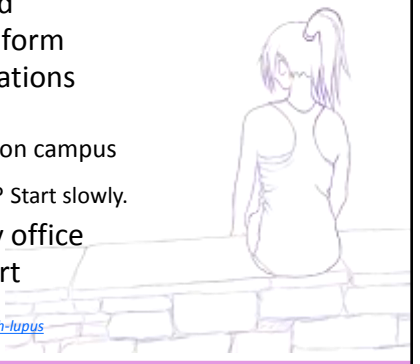
https://s3.amazonaws.com/lupusorgnrcl/PDFdocuments/School_MeetingRequest_Template.pdf?mtime=20171027094028

- Lupus Health Checklist for School

https://s3.amazonaws.com/lupusorgnrcl/PDFocuments/School_Checklist_Template.pdf?mtime=20171027094318

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

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

Thank you!!!

Contact Lupus Foundation of America for more information:

1.800.558.0121

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