

Rheum4You: REPRODUCTIVE HEALTH AND RHEUMATIC DISEASE

Tuesday, September 14, 2021
7 p.m. EDT

AMERICAN COLLEGE
of RHEUMATOLOGY
Empowering Rheumatology Professionals



Our program will begin shortly.



A few housekeeping notes...

- This webinar is being recorded!
- The video will be available at www.SimpleTasks.org.
- Have a question for our panelists? Type it into the Q&A box at the bottom of the webinar screen.



Cheryl Crow
Moderator

- Occupational therapist who has lived with arthritis for 18 years
- Creator of “Arthritis Life” website and podcast series
- Member of the ACR’s Communications and Marketing Committee

The Big Picture

- People with rheumatic disease during pregnancy, pregnancy planning and early parenting have **specific and largely unmet information and support needs**.
- The ACR is committed to providing **accurate, trusted information** about reproductive health and rheumatic disease.
- **A safe and successful pregnancy is possible** with the right planning, information and support!
- **Remember: You are not alone** on this journey – your rheumatology care team is here to support you each step of the way.



Family Planning



Dr. Lisa Sammaritano

Panelist – Family Planning

- Professor of Clinical Medicine at Weill Cornell Medicine; Attending Physician at the Hospital for Special Surgery
- Director of the Rheumatology Reproductive Health Program at the Barbara Volcker Center
- Primary investigator and lead author for the ACR's 2020 Guideline on Reproductive Health and Rheumatic Disease
- Leads reproductive health studies for the Rheumatology Reproductive Health Program at the Hospital for Special Surgery



Dr. Arthur Kavanaugh

Panelist – Family Planning

- Professor of Medicine at the University of California, San Diego
- Director of the Center for Innovative Therapy in the UCSD Division of Rheumatology, Allergy and Immunology
- Contributor to numerous ACR clinical guidelines on the treatment and optimal care of patients with rheumatic disease

Speaking Now



Lisa Sammaritano, MD

Professor of Clinical Medicine
Hospital for Special Surgery
Weill Cornell Medicine

Reproductive Health

1. Family planning
2. Contraception
3. Fertility issues
4. Pre-pregnancy medication assessment

Family Planning

Patients with rheumatic diseases (RD) tend to have fewer children.

Potential contributing factors:

- Sexual disability: physical limitations, pain, fatigue, or reduced sex drive
- Decreased biologic fertility: older age, meds, very active disease
- Teratogenic drugs (potential to cause birth defects)
- Disease impact on pregnancy e.g. miscarriage, other complications
- Pregnancy impact on RD e.g. flare
- Ability to care for a child or concern for passing RD on to a child

Family Planning

For RD patients - in order to have a FAMILY, you need to do the PLANNING

Message: **Most women with RD can have successful pregnancies.
Most people with RD can have children if desired.**

Goal: Plan for well-controlled disease on pregnancy-compatible medications with pre-pregnancy evaluation to identify risks and suggest monitoring / therapy.

Contraception

Important aspect of care for all women with RD who are at risk for pregnancy – if your rheum does not ask you, you should ask them.

Family planning in general usually requires contraception.

Safe use of some rheumatology meds requires contraception.



Pregnancy is discouraged in some patients at certain times:

- Active RD
- Severe disease-related damage that may impart unacceptable risk
- Teratogenic medications may cause birth defects

Pregnancy rates at one year:

Highly effective:

LARC:
IUD or progestin implant <1/100

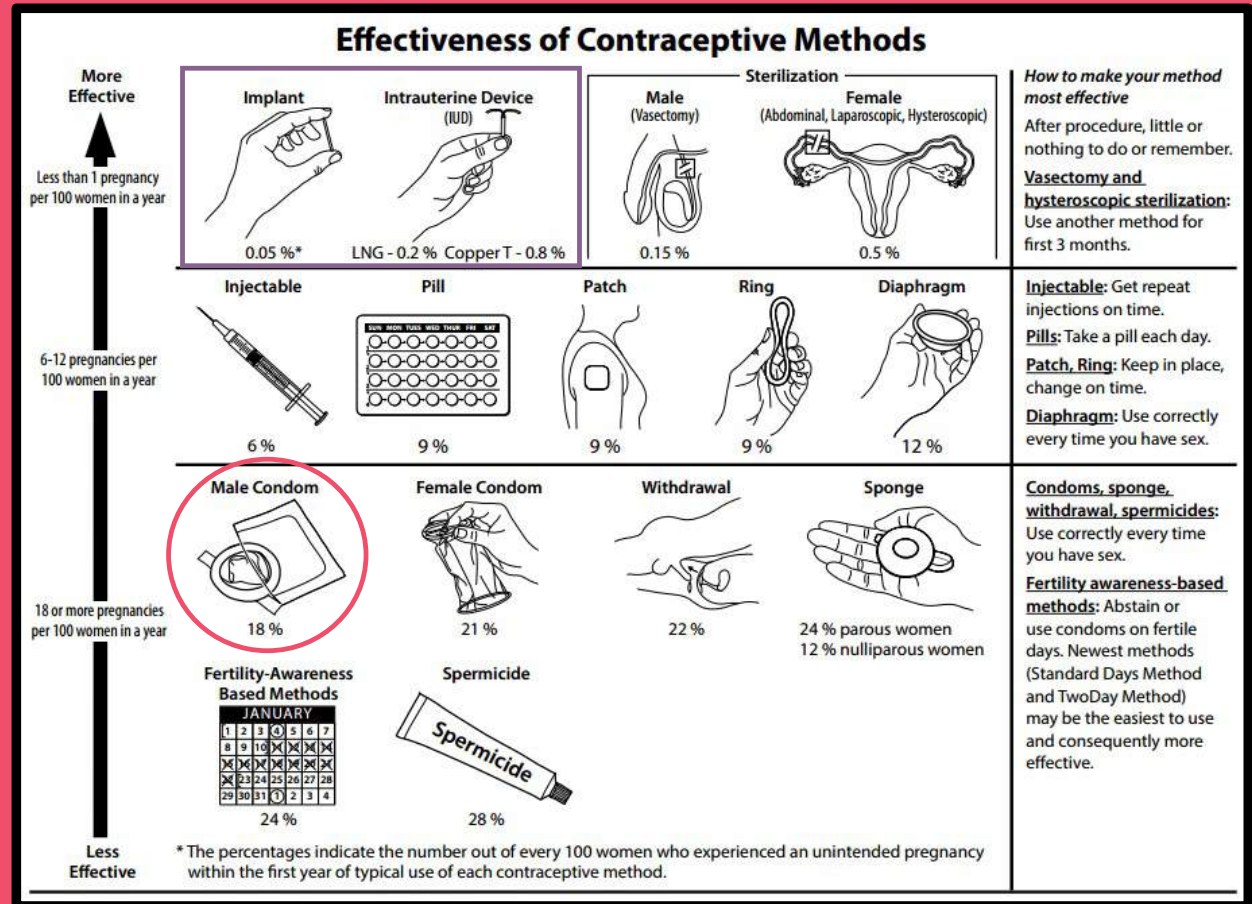
Effective:

Combined estrogen-progestin,
progestin-only pill
1/10 – 1/20

Less effective:

Condom
1/5

LARC = Long-acting reversible contraception.



Long-acting reversible contraceptives (LARC):

Recommended as first-line contraception for all women with RD (including adolescents) – highly effective.

IUD (levonorgestrel or copper) or Implant (etonorgestrel)

If unable or reluctant to use LARC:

- Estrogen-progestin contraceptives (pill, patch or vaginal ring) are safe and effective for RD patients without antiphospholipid antibodies (aPL) or active SLE.
 - Estrogen may increase risk of blood clots in predisposed women and is contraindicated for women with + aPL antibodies.
- Progesterone pill is safe and effective for all RD including + aPL and active SLE.
- Barrier methods are less effective, but condoms do offer some protection against sexually transmitted diseases.

Emergency contraception (OTC progesterone) is safe for all RD patients, including those with + aPL or active SLE.



Contraception in RD Patients

Method	Benefits	Disadvantages
Barrier methods- condom	Lower risk of STD No prescription	Less effective (risk of pregnancy at one year is 18%)
IUD	Highly effective (LARC) Stays in for 3-5 years OK for adolescents Levonorgestrel IUD decreases menstrual blood flow and cramps	Copper IUD may increase menstrual blood flow and cramps No concern for infection risk with immunosuppressive therapy
Combined oral contraceptives	Effective	Potential interactions with medications (mycophenolate) Patch: 60% more estrogen exposure SLE: avoid with active disease (flare risk) aPL: AVOID due to blood clot risk
Progestin-only contraceptives	DMPA injection and progesterone pill effective Implant (LARC) highly effective, lasts 2 years Reduces menstrual blood flow	DMPA injection (not pill) may decrease bone density: AVOID if low density or risk for this DMPA injection may increase risk of blood clots: AVOID if aPL+ or other risk for clots Pill causes irregular breakthrough bleeding

Fertility

Fertility may be impacted by

- Age
- Medications
 - Cyclophosphamide may cause premature ovarian failure
 - NSAIDs may transiently inhibit ovulation
 - High dose corticosteroids may transiently interfere with normal sex hormone feedback loops
- Very active disease

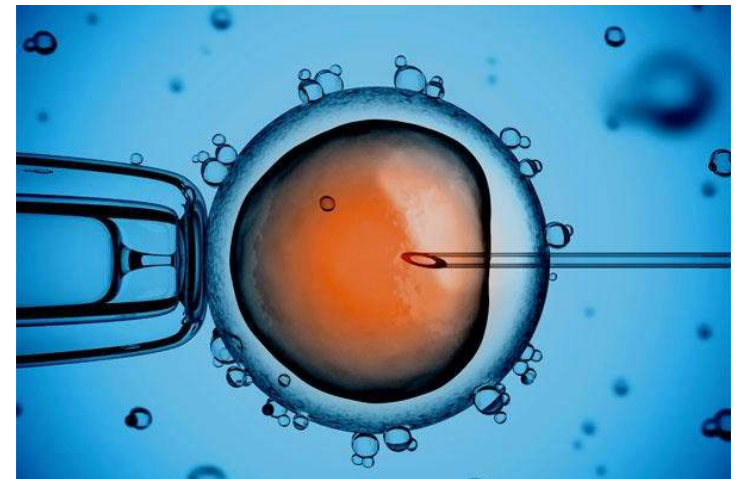
Methotrexate, mycophenolate, azathioprine, tacrolimus and biologic medications do not affect fertility.

20% of (all) couples trying to conceive will encounter difficulty.

Fertility: Use of ART

Assisted reproductive technology (ART):

- Ovarian stimulation (OS) with or without in-vitro fertilization (IVF) and embryo transfer
- Important risks relate to elevated estrogen levels and include **blood clots** (in +aPL) and **flare** (in SLE)
- Oocytes (eggs) or embryos may be cryopreserved (frozen) for later use in the patient (or a surrogate/gestational carrier)



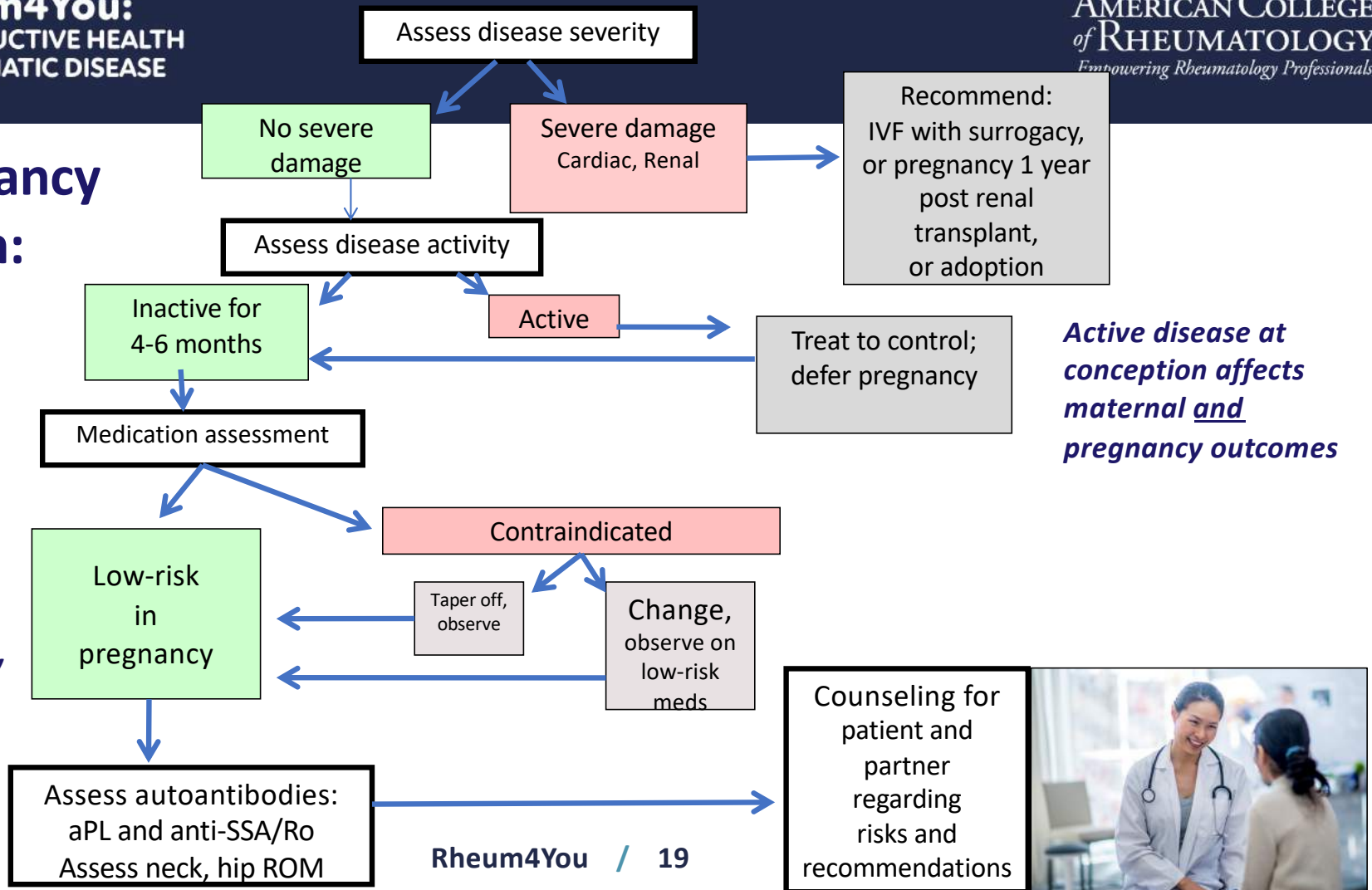
IVF or Egg Freezing in RD Patients

- **Quiet or low-level disease activity:** lower risk of flare
- **Prophylactic or therapeutic dose heparin (blood thinner) for +aPL or APS**
- **Rheumatology should coordinate care with reproductive medicine MD:** Modified ovarian stimulation protocol can reduce max estrogen levels and likely reduce risk for flare and blood clots in patients with SLE or + aPL

If egg or embryo freezing:
Continue current RD meds (exception:
CYC) to avoid risk of flare

If plan immediate embryo transfer for pregnancy:
Change to pregnancy-compatible meds
and observe before beginning IVF cycle

Pre-pregnancy evaluation:



**Active disease at
conception affects
maternal and
pregnancy outcomes**

**Consider
medication use
pre-pregnancy
and by trimester
during pregnancy**



Speaking Now



Arthur Kavanaugh, MD

Professor of Medicine
Director of Center for Innovative Therapy,
Division of Rheumatology, Allergy and
Immunology
University of California San Diego

Family Planning – Male Reproductive Health Standpoint

Family planning male reproductive considerations, particularly if you are being treated for a rheumatologic condition

- Impact of rheumatologic conditions on men's sexual health
- Fertility and rheumatologic conditions
- Treatment considerations for men

Pregnancy





Dr. Megan Clowse

Panelist – Pregnancy

- Associate Professor of Medicine in Rheumatology and Immunology, Director of the Duke Autoimmunity in Pregnancy Clinic
- Has cared for 600+ pregnancies in women with rheumatic disease, collecting information for the Duke Autoimmunity in Pregnancy Registry and the Maternal Autoimmune Disease Research Alliance Registry
- Served on core leadership team for ACR's first Reproductive Health Guideline in 2020
- Creator of www.LupusPregnancy.org

Disclosures

Consultant: UCB, GSK
Grant support: GSK



Pregnancy Loss

Normal
Pregnancy

Low Risk

High Risk



PLANNING!

- Ter
- High
- Un
- Untreated antiphospholipid syndrome (APS)
- Highly active lupus, especially nephritis
- Uncontrolled hypertension
- Untreated antiphospholipid syndrome (APS)
- Untreated antiphospholipid syndrome (APS)

Medications in Pregnancy

Pregnancy Compatible	Caution	Teratogenic
<p>Hydroxychloroquine</p> <p>Sulfasalazine</p> <p>Azathioprine</p> <p>Cyclosporine</p> <p>Tacrolimus</p> <p>Colchicine</p> <p>TNF-inhibitors</p> <ul style="list-style-type: none"> • Certolizumab: continue • Others: consider holding last 1-2 months to limit transfer <p>Prednisone (<i>use sparingly</i>)</p>	<p>Biologics beyond TNF-inhibitors</p> <p>Leflunomide (washout with cholestyramine)</p> <p>New small molecules (tofacitinib, baricitinib, apremilast, etc.)</p> <p>NSAIDs</p>	<p><i>Worst:</i></p> <ul style="list-style-type: none"> • ~40% loss & ~25% defects <p>Mycophenolate</p> <p>Cyclophosphamide</p> <p>Thalidomide</p> <p><i>Less bad:</i></p> <ul style="list-style-type: none"> • ~40% loss & ~8% defects <p>Methotrexate</p>

Lactation

Women do NOT need to choose between themselves or their baby.

Lactation Compatible	Caution	Worrisome (<i>but little data</i>)
Hydroxychloroquine Sulfasalazine Azathioprine Colchicine NSAIDs (<i>prefer ibuprofen</i>) TNF-inhibitors Prednisone ($\leq 20\text{mg}$) Biologics beyond TNF-inhibitors	Methotrexate Prednisone ($>20\text{mg}$)	Leflunomide Mycophenolate Cyclophosphamide New small molecules



www.LupusPregnancy.org
Information, Handouts, CMEs,
Patient Perspective Videos, Dot-
phrases

Preparing for Pregnancy: A Checklist for Patients & Providers



A one-page printable checklist for patients and providers to use to prepare for a healthy pregnancy with Lupus. [Learn more](#)

Birth Control for Women with Lupus



A one-page printable guide to birth control methods including recommendations for women at high risk for blood clots. [Learn more](#)



Parenting



Mariah Leach

Panelist – Parenting

- Writer, patient advocate, and mom of three living with rheumatoid arthritis
- Creator of [Mamas Facing Forward](#), an online community that provides resources, encouragement, and support for moms and moms-to-be living with chronic illness



Rebecca Gillett

Panelist – Parenting

- Occupational therapist who lives with rheumatoid arthritis and osteoarthritis
- Director of Content Strategy & Planning for the Arthritis Foundation
- Host of the Live Yes! With Arthritis podcast

Speaking Now



Mariah Leach

Patient Advocate

Founder of Mamas Facing
Forward



You can't pour from an empty cup.
Fill your own cup first.





Before baby is born:

- Have a plan in place with your rheumatologist.
- Prepare your house.
- If you can, schedule some help.
- Research, buy, assemble, and test baby gear in advance.

**A few of
my
favorite
baby
things...**



Pajamas with ZIPPERS!!!



Co-sleeper



Car seat opener



Hands-free pumping bra



Nursing pillow



Baby carrier



Don't feel guilty about changing your mind!

“I think most people have a list in their mind of what they're going to do and what they're not going to do as a parent. I think it's important, if you're a mom with a disability, to be open to that list changing as you go and as your child grows.”

- Stephanie Aleite, theyoungfaceofarthritis.com

“This group gave me all the hope I needed when I was first diagnosed. Before this group I thought I wasn’t going to be able to have any more kids or be the mother I wanted to be.”

- Mamas Facing Forward group member



“When I was first diagnosed, I was concerned my childbearing days were over. I would like one more child and this group has given me hope and some good information that pregnancy with RA is possible and happens all the time.”

- Mamas Facing Forward group member

Speaking Now



Rebecca Gillett, MS OTR/L

Occupational Therapist, Insight Wellness LLC

Director of Content Strategy & Planning, Arthritis Foundation

Host, “Live Yes! With Arthritis” Podcast

It's All in the Planning

Before Baby arrives...

- Establish a good pain treatment plan
- Implement a good self-care routine & habits
- Determine what physical activity routine works and schedule it
- Learn how to protect your joints
- Get some sleep
- Ask for a referral to **OT/PT**

After Baby arrives...

- Establish a good pain treatment plan
- Implement a good self-care routine & habits
- Determine what physical activity routine works and schedule it
- Learn how to protect your joints
- Get some sleep
- Ask for a referral to **OT/PT**

How Physical Therapy Can Help

Customize a physical activity program

Pain management, modalities, ROM

Teach proper form with movements

Adapt exercise/movements based on joint needs

Address biomechanical needs & positioning

Provide orthotics & braces as needed

Provide strengthening activities

Pre-hab and Post-surgical rehab

How Occupational Therapy Can Help

Teach joint protection principles

Pain management, modalities, ROM

Customize a physical activity program

Help establish routines & habits

Provide custom orthotics, braces for joints

Assist with adaptive equipment needs

Adapt tasks based on joint needs

Address sleep hygiene & positioning

Energy Conservation, Pacing

Social-emotional coping strategies

Joint Protection Throughout the Journey

Strategies to keep your joints from flaring

■ Pre-pregnancy:

- Learn how to protect your joints, especially with daily tasks that are difficult and require repetitive motion
- Establish a good physical activity routine with a PT or OT
- Know how to manage and treat acute flares (cold vs. hot, rest, etc.)
- Spread out your activities and chores
- Address sleep issues and habits

Joint Protection Throughout the Journey

Strategies to keep your joints from flaring

■ **During pregnancy:**

- Re-evaluate your physical activity routine with PT/OT; modify as needed – new center of gravity
- Ask OT and other moms about adaptive tools & tricks
- Plan out your baby preparation and give yourself time to finish
- Get organized to help keep your routine
- Plan and delegate house chores
- Listen to your body, rest!

Joint Protection Throughout the Journey

Strategies to keep your joints from flaring

■ After baby arrives:

- Delegate, divide & conquer chores
- Designate a feeding to someone else so you can sleep
- Wear braces, orthotics to give your joints rest and support
- Get the gadgets
- Visit your OT/PT for any changing needs
- Ask for help
- Listen to your body, rest!
- Enjoy these precious moments. The laundry can wait.



Divide & Conquer

Chores & Tasks

- Communicate your wants and needs with family
- Establish a “help” pain scale
 - 1-2: baseline, can do usual things
 - 3-4: moving slower, having pain, need extra time, some help
 - 5-6: pain is consistent, can do some things, but pain is limiting
 - 7-8: you’re on your own, I need help; pain is too much
 - 9-10: need to go to dr, hospital and all the help I can get
- Regular family meetings to review upcoming week and events
- Create a daily chore schedule; assign difficult task to others
- Spread out chores to conserve energy
- Let It Go...

Adapting the Tasks

Carrying & picking up your baby

- Carry closer to your body
- Wear your baby
- Use larger joints

Breastfeeding

- Positioning (lying down, football hold)
- Use props (nursing pillows, boppy, wedges)
- Pump & use bottles (also gives time for others to feed & time to rest for you)

Bathing/Dressing

- Counter height to avoid bending while small
- Use a stool/chair to sit on next to tub
- Dressing fasteners that are easier (Velcro vs. tiny snaps)

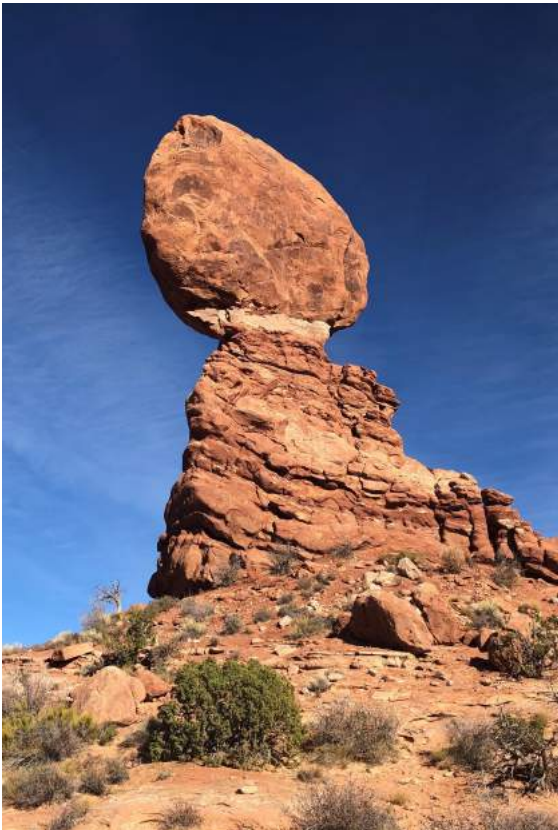
Infant carriers & car seats

- Research/shop for lightweight
- Leave the carrier in, take baby out
- Adaptive tools for car seat buckles

Feeding

- Prep ahead for week with some help
- Larger handles or build up grasp
- Utilize adaptive equipment kitchen tools





Parenting & Self-Care

- Finding balance is hard
- Put your oxygen mask on first
- Plan ahead
- Ask for help
- Schedule your self-care must-haves
- Establish a routine for baby & you

Parenting a Child with Rheumatic Disease

- Arthritis Foundation's JA Power Pack: *Raising a Child With Arthritis*
- Connect with other JA families & kids
- Ask for referrals to OT/PT
- Establish a routine to incorporate pain management, movement
- Plan ahead and know your treatment plan for flares
- Keep a journal/record
- Make time for laughter and fun

Questions?

