Raising the Voice of Patients

A PATIENT'S GUIDE TO PREGNANCY AND FAMILY PLANNING WITH RHEUMATIC DISEASES

First Edition

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PART ONE

Introduction

Is there any event in your life more joyous—and stressful—than having a baby? Every parent wants to do whatever possible to ensure a healthy baby, smooth pregnancy and safe delivery.

If you are living with a rheumatic disease like rheumatoid arthritis (RA), psoriatic arthritis (PsA), ankylosing spondylitis (AS), systemic lupus erythematosus (SLE or lupus) or others, you probably have lots of questions and concerns about starting a family.

- Will my disease affect my fertility and make it harder to conceive?
- Will my medications affect my baby's health or development?
- Will my disease raise my risk of pregnancy complications?
- Will pregnancy affect my immune system, and if so, how?
- Will my disease make my delivery more complicated?
- Will I feel well enough for pregnancy, delivery, breastfeeding or caring for my new baby?
- Will my arthritis flare if I stop my meds during pregnancy, triggering joint damage or severe pain?
- Can I start taking my arthritis treatments after delivery, or do I have to hold off if I want to breastfeed?
- Will I be able to breastfeed?
- Will my kids also have my rheumatic disease?

All of these questions are very important, but one thing you should know now that will help you put your mind at ease: People who have rheumatic diseases often have safe, uneventful pregnancies. They are able to adapt their lives to have healthy babies. They breastfeed their babies and care for them just as any other parent does. Their children grow up to lead healthy, active, full lives. It might not always be easy, but it is possible.

However, RA, PsA, AS, lupus and other rheumatic diseases like antiphospholipid syndrome (APS) can increase your risk of complications during pregnancy. Some medications for rheumatic diseases can harm a fetus and cause birth defects if you are taking them when you conceive or during the early parts of your pregnancy. And having a rheumatic disease or living with its effects, like joint damage or pain, can make pregnancy or caring for your baby more challenging.

So it's smart to plan ahead **before** you start your family. That's why we created this helpful guide to family planning for people with rheumatic diseases. In this guide, you'll find some information to help you understand your risks and how to work with your doctors to manage them. You'll find questions to ask your **rheumatologist** and **obstetrician/gynecologist (ob/gyn)** about starting a family, from conception to pregnancy to delivery to breastfeeding.

A great peer run support group can found by visiting **Mamas Facing Forward** on Facebook:
https://www.facebook.com/groups/mamasfacingforward

PART TWO

Do Rheumatic Diseases Affect Fertility?

Most people think about starting a family at some point. People with rheumatic diseases are no different. However, they may wonder if their disease could make it harder for them to conceive.

There is evidence that shows that women with RA can take longer to conceive than women who do not have the disease. One key factor is that women who have rheumatic conditions are recommended to wait until their disease is controlled for at least 3-6 months before trying to conceive. Other factors can influence a woman's ability to conceive: high disease activity, taking non-steroidal anti-inflammatory drugs (NSAIDs) or corticosteroids for inflammation, and increased age when pregnancy is attempted. One recent study showed that often, women with RA who are trying to conceive take longer than 12 months to be successful.

Another study showed that women with RA and lupus had fewer children throughout their lifetimes compared to the general population. However, that may be due to various factors. Women with a serious disease may worry about being healthy enough to be pregnant or care for a child, or have concerns about the impact of their medications on their unborn baby. Those fears may cause them to delay or avoid conception. Women whose disease activity is not well controlled may decide to delay or forgo having a baby. This is a personal decision based on many factors.

Women with lupus have to also consider whether they are healthy enough to get pregnant. Having active inflammation or scarring in the kidneys, lungs or heart can make a pregnancy high risk to both the mother and any potential offspring. If you have a history of any of these complications or blood clots, you should talk with your rheumatologist and a high-risk obstetrician (also called a maternal-fetal medicine specialist or a perinatologist) before pregnancy.

Do Rheumatic Diseases Affect Fertility?

Prior treatment with cyclophosphamide can cause damage to the ovaries in some woman and may make it hard to conceive.

Men who take sulfasalazine (*Azulfidine*) or colchicine (*Colcrys*) may have temporarily reduced fertility. To find out if this is happening, simple tests to measure your sperm quality or count can be done by a fertility doctor or urologist. Within 3-6 months of stopping these medications the sperm generally return to normal, so if you seem to have reduced fertility discuss holding these medications temporarily.

There are also general lifestyle factors that can make it harder to conceive, such as smoking or heavy drinking. Women with rheumatic diseases may have these habits just as other women do, and need to work with their doctors to "kick the habit" if they want to improve their chances of getting pregnant. Smoking and drinking, especially if you take certain medications for your disease, could be dangerous to your health.

There are many factors that could make it more challenging for you to conceive. But you *can* work with your rheumatologist to change some of these factors, as well as the stress that comes with them. Your rheumatologist may be able to adjust your treatment plan to get your disease activity under control. You can switch to different medications to control your symptoms if the ones you use now make it harder to get pregnant. If you've delayed trying to get pregnant for any reason—and some reasons may have nothing to do with your disease—you can talk with your rheumatologist and your ob/gyn about all of your options to start a family. Information is your best tool.

If you do have trouble getting pregnant, you may need to explore assisted reproduction techniques (ART) like ovulation induction therapy or *in vitro* fertilization. Your rheumatologist and ob/gyn can refer you to a specialist that can counsel you on these techniques, and any other options for you and your partner to start a family. For women with RA and other forms of inflammatory arthritis, there are generally no restrictions on the types of fertility treatments considered safe. For women with lupus, your physician may consider modifying their usual treatments somewhat to make it safer for you

There isn't current data about fertility in people with psoriasis, psoriatic arthritis and ankylosing spondylitis. Some studies show that more women with psoriasis or psoriatic arthritis may have an increased risk of polycystic ovarian syndrome, which causes irregular periods, excess hair growth, and can be associated with diabetes. If you have any of these symptoms, talk with your gynecologist or primary-care doctor to see if you have the syndrome, as treatment can make it easier for you to conceive.

PART THREE

Family Planning

HOW TO START THE PROCESS

As we have noted, it's best to start planning for pregnancy or starting a family BEFORE you try to conceive. Your rheumatologist and obstetrician can help guide you through the process, make changes to your medications if necessary, and direct you to other specialists or resources to improve your chances of getting pregnant and having a healthy baby.

Remember: You are unique. Your rheumatic disease, your overall health, your medical history and your lifestyle are not like those of anyone else. So your doctors will take your personal situation into account as you begin your family planning process. Try not to compare yourself to other women you know, such as family members or friends. Their pregnancy and labor or delivery experiences may not be what you will experience. These differences may have nothing to do with your illness.

As you work with your rheumatologist and ob/gyn on family planning, listen to their advice, your body, and do research to find trusted and evidence-based information. Your doctors have the training, expertise, information AND knowledge of your medical conditions to provide you with the most meaningful guidance, but don't hesitate to seek second opinions from other trusted health professionals.

Your family planning and prenatal care should be tailored to suit your medical and personal needs. Here are some general elements of family planning for people with a rheumatic disease:

YOUR GOALS FOR A HEALTHY PREGNANCY

As you plan to start your family, you probably have two main goals: **manage your disease** and **protect your baby's health.** Your rheumatologist and ob/gyn will work with you on important questions like these:

- When you or your partner should stop taking certain medications to "clear" them from the body before conception;
- What medications are safe to continue while trying to conceive, during pregnancy, and/or during breastfeeding;
- When you should get any vaccines or immunizations before trying to get pregnant and/or stopping any medications;
- How to manage you or your partner's rheumatic disease while off these medications, including using other treatments during this time;
- When to begin trying to conceive your baby, taking your overall health into account;
- How to manage your disease during pregnancy;
- What symptoms to watch for during pregnancy that could signal complications to be addressed;
- What steps you can take to help support your and your baby's health during pregnancy;
- How to plan for delivery and caring for your baby in the first few weeks at home; and
- How to manage your disease after pregnancy to reach your breastfeeding goals.

FAMILY PLANNING: IT'S FOR EVERYONE (GUYS TOO)

It's not just women with rheumatic diseases who need to plan carefully for pregnancy. If you're a man or gender non-conforming individual with a rheumatic disease, and you and your partner want to conceive, your medications could also affect your unborn baby.

So you need to do what you can to prevent unplanned pregnancies until you are ready to conceive. A few of the medications that treat rheumatic diseases, especially methotrexate, mycophenolate, cyclophosphamide and leflunomide can cause pregnancy loss or birth defects. It is important to avoid pregnancy *while* taking them, and in some cases for a period of time *after* ending them (see section on Medications for details).

Family planning consultation with your rheumatologist, ob/gyn and/or a maternal/fetal specialist: Before you and your partner try to conceive, you can meet with your doctors to screen for factors that may make conception more difficult, or to identify medical conditions, and medications or lifestyle factors that could negatively impact fertility. Your rheumatologist can create a plan for you to stop taking any medications, such as methotrexate, leflunomide, mycophenolate, cyclophosphamide or others, that could be harmful to your unborn baby. We'll go over the specific drugs used to treat rheumatic diseases and how they may affect you or your fetus later in this guide.

It's recommended that you see your rheumatologist about three to six months before you try to get pregnant to make sure your disease is under control. Your rheumatologist can help you switch your medication regime if needed, during pregnancy – some medications may need to be stopped but others can be started to replace these. This allows you to keep your arthritis controlled in a way that may be safer for your baby. Keeping your arthritis under control is important since active inflammation can make it more difficult to conceive or increase the risk of negative pregnancy outcomes.

Remember: Don't stop taking your medications on your own. Work with your doctor to cycle off these medications or make changes to your treatment plan. Your rheumatologist and ob/gyn need to know all the prescription or over-the-counter medications you are taking or have taken recently. That includes medications you may take for reasons other than your arthritis. You should also tell your rheumatologist and ob/gyn about any herbs, supplements or vitamins you take.

What about recreational drugs such as marijuana, cocaine or others? Many doctors screen for drugs and alcohol on standard prenatal tests. If you use drugs, it may show up on these tests.

Recreational drug use during pregnancy could put your baby's health at risk. This is a controversial issue for many women, who may not want to tell their doctor that they use illegal drugs out of fear of legal repercussions. While only you can make the decision about what to tell your doctor, be aware that these drugs can put your baby's health at risk, and that marijuana and other substances may show up on your screening tests.

Contraception consultation:
If your rheumatologist advises you to wait to try to conceive until your body is clear of certain medications or your disease is in remission, you'll need to know about contraception. There are many different options to prevent pregnancy. Your doctor can give you information about these options, and how they may work for you and your lifestyle or budget. Don't be ashamed to ask questions or be completely honest with your doctor about your sex life, or any concerns you have about contraception side effects or effectiveness. Ask any frank questions you have about how to properly use any form of contraception. It's better to know what you're doing than to take the chance on an unexpected pregnancy.

BIRTH CONTROL OPTIONS: It's very important to plan for any pregnancy if you have a rheumatic disease. Unplanned or unexpected pregnancy could put your health and your baby's health at risk.

There are many different birth control methods that can help you prevent unplanned pregnancy. There are hormonal birth control pills, patches, shots and implants. There are intrauterine devices (IUDs), diaphragms and cervical caps. There are condoms that block sperm from entering the uterus. You can also choose to abstain from unprotected intercourse until you're ready to conceive. How do you know what's right for you?

How you choose to prevent an unplanned pregnancy is a very personal decision. Your unique situation, budget, insurance coverage, lifestyle, faith or culture, and past experiences may influence which birth control methods you decide to use. You and your partner may have different preferences about the method you use too, so it's helpful to have a conversation about this topic. Be open about your feelings or concerns.

If you aren't planning on getting pregnant for more than a year, then the most effective forms of birth control are an implant (*Nexplanon*) under the skin of your upper arm, or the IUD (intrauterine device), which is inserted into your uterus. Your ob / gyn doctor puts these in place during an office appointment. Once you are ready to conceive, make an appointment with your doctor to have the IUD removed. These birth control options may help you ease your worries about getting pregnant before you are ready. No birth control method is foolproof, but the implant and IUD both have high rates of success if used properly.

Your doctor can go over all of your birth control options, and explain the risks and benefits to you. Speak up if you have any questions, including how effective they are at preventing pregnancy, how to use them properly, how much they cost (including out-of-pocket costs or copayments) and what side effects are possible. Be sure to tell your ob/gyn about your rheumatic disease, your medical history and any medications you take. This information will help you and your doctor find the best birth control choice for your needs.

For women with lupus -- screening for antiphospholipid (aPL), anti-Ro/SSA or anti-La/SSA antibodies:
Women with lupus are typically tested for these antibodies. If you test positive twice for high levels of aPL (over 40 units), these antibodies can put you at risk for blood clots, as well as pregnancy loss. Your rheumatologist and obstetrician will consider adding aspirin, and sometimes a stronger blood thinner, to your treatment regimen during pregnancy.

The offspring of pregnant women who test positive for anti-Ro/SSA antibodies are at risk for developing a permanently slow heartbeat (congenital heart block) or a rash. It is important to screen for these antibodies before conception so you can know the risks. Your doctor might recommend extra medications to decrease the risk of the heart problems and ultrasounds to monitor for them during pregnancy.

Prenatal vitamins:
Ideally, start taking prenatal vitamins BEFORE you get pregnant! They have their biggest impact on the fetus in the initial weeks of pregnancy, often before you even know you're pregnant. Your doctor can give you a prescription for prenatal vitamins, but you can buy them over the counter at any pharmacy or supermarket (they all contain the same stuff). Consult with your ob/gyn for recommendations.

Prenatal care:
Your rheumatologist will supervise any medication changes you make before or at the beginning of your pregnancy. Your doctor can also advise you on prenatal vitamins or supplements you should take, such as folic acid, and ensure

that your immunizations are up to date. Your rheumatologist and ob/gyn can both advise you on any changes you should make to your diet, your exercise or physical activity routine, weight management and other lifestyle factors. It's important to stay active during your pregnancy, including range-of-motion exercises to keep your joints flexible.

If you flare:
Your rheumatologist can schedule regular office visits during your pregnancy to monitor you for any symptoms of a flare. If your disease symptoms flare during your pregnancy, don't panic! Your rheumatologist can prescribe safe treatments to help you lower your inflammation, control your symptoms and feel better. Post-partum flares are very common, so plan to meet with your rheumatologist soon after delivery.

Regular appointments:
How often do you need to see your rheumatologist during your pregnancy? It depends on your condition and if you have any flares during your pregnancy. In one recent study, 43% of pregnant moms with RA saw their rheumatologists once a month during their pregnancies, but 42% only saw their rheumatologists once every trimester and 14% only once during their entire pregnancy. Your rheumatologist can advise you on how often you will need to come into the office for a check-up.

If you have lupus or are deemed high-risk, you may need to see your rheumatologist more often during your pregnancy. Your obstetrician should get routine ultrasounds at about 11-14 weeks and 20-24 weeks. In your third trimester, more frequent ultrasounds are recommended to spot any problems with your baby's growth or healthy heart development. If you have tested positive for anti-Ro/SSA antibodies, repeated fetal echocardiograms may be recommended to identify early changes in the heart rhythm.

PART FOUR

Rheumatic Diseases and Pregnancy

How does pregnancy affect women with certain rheumatic diseases, and how can having those diseases complicate pregnancy for some women? One important factor is disease activity. Disease activity can change during pregnancy in some cases, and it can also increase your risk of pregnancy complications.

If you have an autoimmune rheumatic disease like RA or others, you already know about disease activity. This term describes your levels of inflammation, and the effects of high inflammation on your body: joint pain or swelling, inflamed skin or eyes, impaired mobility, severe fatigue, nausea and other symptoms.

During pregnancy, you will work with your doctors to use medications that are compatible with pregnancy to control disease activity and lower your inflammation. Keeping your disease activity under control helps you manage your symptoms and prevent long-term damage to joints, tissues and organs.

Pregnancy can trigger short-term changes to your immune system. This is a natural effect of pregnancy, and helps the fetus grow and develop. For some women, these immune system changes can lower their disease activity during pregnancy. They experience an improvement in their symptoms, and have less pain or fatigue that they did prior to pregnancy. However, there are many women who do not. The most recent studies show that about half of women with RA, for example, improve during pregnancy while half continue to have active disease.

Telling the difference between pregnancy and flares: When you are pregnant, you may feel symptoms that are pretty similar to those of your rheumatic disease:

- Low back pain
- Fatigue
- Nausea
- Swollen ankles, feet or hands

At your medical appointments during your pregnancy, your rheumatologist and ob/gyn can keep track of your symptoms, and assess whether they are due to your rheumatic disease or symptoms of being pregnant. You can work with your doctors to treat your symptoms.

Here is a good guide: If your symptoms feel similar to your typical flare, then they probably are from your rheumatic disease. If they feel different from your usual symptoms, then it's more likely that they are due to pregnancy.

STRESS AFFECTS PREGNANCY TOO: People with chronic diseases like arthritis often have high levels of stress, anxiety or even depression. It's stressful to deal with an ongoing illness that can cause severe symptoms, and requires regularly taking treatments that may have unpleasant side effects. People with rheumatic diseases often have to juggle doctor appointments, injections and pills, and insurance approvals for treatments.

Stress from your chronic disease can affect your overall health. It can affect your sleep and energy levels. While it is tempting to relieve stress in unhealthy ways, like smoking, drinking too much alcohol, taking drugs or overeating, all of these habits are especially risky during pregnancy. Pregnant moms are strongly advised not to smoke or drink alcohol. Obesity can also increase the risk of pregnancy complications like gestational diabetes.

If you find it hard to control your stress or anxiety due to your rheumatic disease, talk to your rheumatologist. Counseling or other mental-health treatment may help you get your stress under control. If you smoke, regularly drink alcohol, take any recreational drugs or overeat as a way to deal with the stress from your disease, you should get help before you get pregnant if possible.

Rheumatic Diseases and Pregnancy

Pregnancy may affect different rheumatic diseases in unique ways. Depending on your specific condition and how well controlled your disease is at the time you conceive, you may be at risk for certain complications. On the other hand, pregnancy might make your symptoms lessen temporarily. Here's a quick overview of what you might expect:

▼ Rheumatoid Arthritis (RA):

Rheumatoid arthritis (RA) is an autoimmune disease. The body's immune system, which normally triggers inflammation as a way to fight off disease, attacks the body's tissues instead.

RA is chronic, and out-of-control inflammation can cause pain, swelling, stiffness and impaired function of the body's joints. Many joints may be affected, such as the hands, wrists, fingers, knees, shoulders, hips, neck, feet or ankles. People with RA whose disease activity is not well managed by treatments can experience damage to their joints that causes permanent disability. Inflammation may also affect organs like the eyes, heart, lungs or kidneys in some people with RA.

RA's pain and fatigue may make women worry how bad they'll feel when they're pregnant. However, many women (about half) with RA actually experience lowered disease activity during pregnancy. There is evidence that this varies depending on the patient, but symptoms like pain or fatigue may noticeably improve starting in the first trimester all the way through their delivery. Some pregnant women with RA even see their disease go into remission during this time. Why? During pregnancy, fetal DNA cells circulate through the mother's system also. These fetal DNA cells increase throughout the pregnancy, and as they do, RA disease activity often goes down. As a result, some moms with RA feel better while they're pregnant.

After delivery, however, RA disease activity most often comes back. New mothers often experience disease flares. Symptoms like pain and fatigue can return after you have your baby.

Please note that many people share the false information that women go into remission during pregnancy. The expectations of both patient and physician that RA will go into remission during pregnancy may lead to undertreatment based on unfounded optimism.

As a result, you may have debilitating symptoms just as your newborn baby needs a lot of care. Talk to your rheumatologist about treatment options and getting back on medications BEFORE your RA flares. You may be able to start taking RA medications just a few weeks after your delivery to get your disease activity under control. Many medications for RA are safe with breastfeeding, so your rheumatologist can prescribe treatments that are safe to use as you nurse your baby.

Please note that all people are different and because some women experienced a reduction in symptoms doesn't mean that you will too.

▼ Psoriatic Arthritis (PsA)

Psoriatic arthritis (PsA) is a chronic, inflammatory type of arthritis. People who have psoriasis, a type of scaly skin rash, may also develop joint pain and stiffness, swollen digits, nail pitting, fatigue or other symptoms.

There is much less data about how PsA changes in pregnancy, but most women don't see a big change in arthritis activity during pregnancy or after pregnancy. A recent study of 42 PsA pregnancies found that 58.5% of patients noted improved or low disease activity, while 31.7% had worsening or ongoing high disease activity during pregnancy.

Psoriasis, on the other- hand, may improve in some women and worsen after delivery.

Risks of PsA during pregnancy may be due to how well the mother's disease activity is controlled. When disease activity is high, your immune system produces an excessive amount of inflammatory agents called cytokines. High levels of cytokines in the blood can affect the baby's growth in the uterus, and lead to low birth weight. So it's a good

idea to work with your rheumatologist to lower your disease activity before you try to conceive, and keep it under control while you are pregnant.

▼ Ankylosing Spondylitis (AS)

Ankylosing spondylitis (AS) is a chronic disease that causes inflammation of the spine. It usually progresses over time. Back pain is the most common symptom. AS is one of a group of diseases called spondyloarthropathies that includes PsA too. People with the gene HLA-B27 are susceptible to developing AS, but not everyone with this gene gets the disease.

AS inflammation usually affects the sacroiliac joints of the lower spine, but may be found in other joints like the feet, shoulders, ribs, knees and hips. AS often affects the entheses, or the places where tendons and ligaments attach to bones at the joints. Organs like the eyes and bowels may also become inflamed, and more rarely, the heart and lungs.

There is limited data about how AS changes in pregnancy, but most women have symptoms in pregnancy that are fairly similar to their symptoms before pregnancy. So if you have low back pain or other problems, you'll probably still have these when you're pregnant. Talk with your rheumatologist about ways to treat symptoms like back pain or inflamed bowels during your pregnancy.

Moms with AS are probably just as likely as any other women to carry their babies to full term, and give birth to healthy babies. However, AS may cause problems for women after delivery as they try to care for their newborn baby. Around 65% of women with AS in one study had trouble with physical tasks related to caring for their newborn because of their symptoms: lifting, carrying or bathing, for example. This is not just a problem for women with AS, but is common for all women with arthritis of any kind.

Women with AS whose disease activity is not well controlled when they conceive often experience aggravated symptoms during their pregnancy, and strong flares after delivery. In one study, 60% of women had a flare within six months of giving birth.

Women with AS whose disease is not well controlled may have severe lower back pain or stiffness. This could make delivery more difficult in some cases. It may be harder for you to keep your legs open during a long labor. Severe spine stiffness may affect your ability to have an epidural, which numbs the lower body during labor. Talk to your doctor about how to manage your pain or stiffness during labor.

Because AS is caused by the HLA-B27 gene, your baby may inherit the gene too. This doesn't mean that your child will grow up to develop active AS, but he or she may be susceptible to it. Couples can have genetic testing and counseling prior to conception to learn more about the risk of their baby developing AS, and what signs to watch for as the baby grows up.

▼ Systemic Lupus Erythematosus (SLE or lupus)

Systemic lupus erythematosus, more often just called lupus, is a chronic, inflammatory disease that may affect the skin, joints and multiple internal organs, such as the lungs, kidneys, heart or brain.

Lupus is an autoimmune disease that typically involves more parts of the body than RA or PsA. The body's immune system attacks healthy tissues and organs by mistake, and inflammation can rage out of control.

Lupus most often affects young women who are in their childbearing years. Decades ago, women with lupus were once advised to avoid pregnancy. Now, effective treatments allow women with lupus to better control their disease activity and have safe, healthy pregnancies.

Women with lupus are more likely to have a flare during pregnancy, experience pregnancy loss or preterm birth, or experience other complications if they have any of these health problems: pre-existing or current hypertension (high blood pressure), history or current kidney disease, history of preeclampsia during pregnancy, history of blood clots

or low blood platelets, or antiphospholipid antibodies.

In addition to your rheumatologist, you will likely need to see a maternal-fetal specialist during your pregnancy. This is an obstetrician who specializes in managing high-risk pregnancies. Women with lupus need to follow their doctors' instructions carefully, watch for any signs of health problems or pregnancy complications, get enough rest and exercise, eat a healthy diet, and take any prescribed medications as directed.

You'll need to get regular tests like these during your pregnancy to check for possible complications:

- Urinalysis
- Complete blood count (CBC)
- Kidney and liver function tests
- Antiphospholipid antibody tests
- Anti-SSA/Ro and anti-SSB-La antibody tests
- Anti-DNA antibody tests
- Complement tests (C3 and C4)
- Fetal ultrasounds

Pregnant women with lupus should see their rheumatologist about once every trimester, although your doctor may recommend more frequent appointments. If you have a flare during pregnancy, you may need to see your rheumatologist more often.

Controlling lupus during pregnancy, and avoiding flares, is the best way to have a safe pregnancy and healthy baby. Your rheumatologist can prescribe treatments like hydroxychloroquine (*Plaquenil)*, azathioprine (*Imuran*), or prednisone during pregnancy to control your lupus.

Women with lupus are more likely to have a preterm delivery, meaning the baby is born more than three weeks before the due date. In some cases, the baby is born a month early and is very healthy, but perhaps a bit small. In other cases, the baby is born several months early and is in the hospital for many weeks and can suffer life-long complications. Very active lupus, particularly in the kidneys, is the most common cause for a very early delivery.

Unfortunately, women with lupus are at increased risk for miscarriages and stillbirths. Previous miscarriages and/or high levels of antiphospholipid antibodies are the most worrisome risk factors for this outcome. Women who have active lupus nephritis (lupus that involves the kidneys) at the time they conceived, or women who test positive for high protein levels in the urine, antiphospholipid antibodies or lupus anticoagulant; or have hypertension or high serum creatinine levels during pregnancy may also be at higher risk for losing their baby.

Lupus can increase the risk of certain serious pregnancy complications. That's why regular visits with your maternal-fetal specialist for blood and urine tests are so important. These complications include:

- **Preeclampsia**, or pregnancy-induced hypertension: This used to be called toxemia, and is caused by problems with the baby's placenta. The placenta is an organ attached to the uterine wall and connected by the umbilical cord to the fetus that allows for the flow of blood, oxygen, and nutrients. Preeclampsia occurs after 20 weeks, and causes sudden high blood pressure, high levels of protein in your urine, and can cause severe headaches, blurred vision, and seizures. Preeclampsia is a serious complication that could arm you and your baby, so it requires emergency medical treatment. Your doctors are looking for early signs of preeclampsia when they check your urine and blood pressure at every visit.
- **HELLP syndrome**, which stands for hemolysis, elevated liver enzymes and low platelets: This is a somewhat rare syndrome, but can occur in 10% to 20% of women with preeclampsia.
- **Intrauterine growth restriction:** This can cause your baby to be very small and may be due to

hypertension, antiphospholipid antibodies or high lupus disease activity, especially if you have kidney involvement.

- **Kidney problems:** Active lupus can cause reduced kidney function. Extra protein can seep into your urine. This can cause swollen feet, legs or ankles. Pregnant women may think swollen ankles are normal, but if you have lupus, it could be due to impaired kidney function.

Once again, most women with well-controlled lupus can have safe, healthy pregnancies, and give birth to healthy children with no development problems. It's important to see your rheumatologist and maternal-fetal specialist regularly, notify them about any possible problems or signs of complications, and take medications as they direct to control flares.

Neonatal lupus:
Rarely, women with lupus could have a baby with neonatal lupus. Neonatal lupus is NOT the same as SLE; babies born with neonatal lupus are very unlikely to develop chronic lupus later in life. Neonatal lupus is caused by a reaction in the infant to the mother's anti-SSA/Ro antibodies. About 10% of babies will be born with a skin rash that will go away on its own over the first few months of life and won't come back. Occasionally, the infant might have abnormal liver tests or low blood cell counts, but this is also temporary and babies do not need to be specifically tested for these blood tests at birth

In about 1-2% of cases, fetuses exposed to anti-Ro antibodies will develop a congenital heart block, which slows the heartbeat and requires a pacemaker. This happens before the baby is born. Once a baby is born with a normal heart rhythm, there is not a risk of developing this condition.

Antiphospholipid Syndrome (APS)

Antiphospholipid antibodies could put you at risk for serious blood clots that could cause miscarriage if you do get pregnant. Your rheumatologist can test you for antiphospholipid antibodies. If your test is positive, your rheumatologist can counsel you about how your results affect your chances of getting pregnant or carrying a baby to term.

Antiphospholipid antibody syndrome (APS) is an autoimmune disease that can cause blood clots and pregnancy loss. Sometimes women with APS have other rheumatic diseases, usually lupus, but most women with APS do not have another rheumatic disease.

In APS, the high levels of these antibodies hinder normal, healthy blood flow. Blood clots can block arteries and veins, restricting healthy blood flow to the fetus as it develops in the uterus. This can lead to miscarriage or stillbirth.

If you have APS, you may need to take anticoagulants (blood thinners) to maintain healthy blood flow. Injections of heparin or low-molecular weight heparin, blood thinners, and a daily tablet of low-dose aspirin, have been shown to greatly improve the chances of having a successful pregnancy. Blood tests can show high levels of antiphospholipid antibodies that may require treatment during pregnancy. Your rheumatologist will work with you to pick the treatment plan best for you.

If you have APS and want to get pregnant, talk to your rheumatologist and ob/gyn before trying to conceive. You and your doctors can assess your health and risk of blood clots, and come up with a plan to prevent clots during your pregnancy. There are effective treatments to manage APS during pregnancy so you can greatly lower the risk of complications.

PART FIVE

Unplanned Pregnancy: It Happens!

Of course, it's not always possible for you to plan for a pregnancy. Even if you use some form of birth control, unexpected pregnancies can happen. (This is one reason why rheumatologists suggest using two forms until you're ready to conceive.)

You may think that unplanned pregnancies are pretty rare in the era of birth control pills and other modern forms of contraception. But they're not rare at all: A 2011 study by the Centers for Disease Control and Prevention cites that in 2006, almost half of all pregnancies in the United States are unplanned. Rates of unplanned pregnancy do seem to be declining slowly in the U.S., but they're still pretty common. The rates of unintended pregnancy are much higher for women under age 20.

Another important fact: Many women do not know they're pregnant for several weeks after conception. A missed period, which may happen weeks after conception, is the classic first sign of pregnancy. Some women may not find out they're pregnant until six weeks or even longer after conception.

Are you at risk for an unexpected pregnancy? You may think it couldn't happen to you, because you've used birth control for years with no problems. However, it's easier than you think: you might forget to take a birth control pill one day, get your pill schedule mixed up when you're traveling, condoms tear or break, and you might take other medications that can lower the effectiveness of birth control pills. Even with perfect birth control use, things just happen!

If you think you might be pregnant, or if you're a man with a rheumatic disease and your partner thinks she might be pregnant, call your doctor right away. An at-home urine pregnancy test, which you can purchase at the pharmacy or grocery store, can confirm whether or not you're expecting, and if so, your doctor can help you with next steps.

If you're a woman with a rheumatic disease and unexpectedly get pregnant, **don't stop taking your meds on your own**. Call your rheumatologist immediately, and follow the instructions he or she gives you about your treatments.

What will happen to you and your baby if you're taking medications for your RA, PsA, AS or lupus and unexpectedly become pregnant? It's not always easy to tell. There isn't enough data on how most drugs affect a fetus, because these drugs are not tested on pregnant women in clinical trials or post-marketing studies, which is when a drug is studied to check for negative effects over long periods of time. Some drugs may cause birth defects when they're tested on animals, which is how drugs are typically evaluated for safety. But drug tests on animals may use doses that are much higher than humans normally take. Also, some drugs may not affect an animal fetus, but be harmful to humans.

How does your doctor weigh the potential benefits of you or your partner using a drug during conception, pregnancy or breastfeeding with any possible risks to your baby? Studies are conducted of women who take a medication in pregnancy, comparing the health of these pregnancies and offspring to pregnancies not exposed to these drugs. MotherToBaby is the main group running these studies in the U.S., and any pregnant woman with a rheumatic disease who has taken a medication during pregnancy may join these studies. To participate, contact MotherToBaby at contactus@mothertobaby.org. The rest of the research is completed through phone calls, until after delivery when a pediatrician travels to your house to carefully examine your baby. The data from these studies will help women know about the risks and benefits of medication for rheumatic disease in the future.

Want to learn more?
The MotherToBaby website has great information on common medicines used by pregnant women with rheumatic diseases: http://www.mothertobaby.org. It's easy to understand and has lots of useful tips for you as you go through this journey from pregnancy to parenthood.

PART SIX

Arthritis Drugs During Pregnancy: Risks to a Fetus or Newborn

Information about medication safety is always changing as new research comes out. As a result, and because no two patients are the same, it is always a good idea to have a conversation with your rheumatologist about your treatment plan and how it might change during pregnancy and the months after.

Some medications used to treat rheumatic diseases are considered compatible with pregnancy based on data that show no risk to the fetus or pregnancy. You can continue using these medications while you are trying to conceive and stay on them once you are pregnant. Talk with your rheumatologist if you have any questions, concerns or fears.

Other medications may cause pregnancy loss or birth defects, including harming the fetus. If you take any of these medications, it is recommended that you stop them prior to getting pregnant to avoid causing any harm to your baby. Some medications are long-lasting and need to be stopped well in advance of pregnancy (e.g., leflunomide).

Pregnancy registries are increasingly being used to monitor the impact of medications in pregnancy. If you and your provider decide you should continue your medication during pregnancy or breastfeeding, you can get in touch with Mother to Baby or Infant Risk to participate in one.

Which arthritis drugs could be risky for an unborn baby and why? You can check several professional resources on this topic, such as Thomas Hale's guide "Medication and Mother's Milk," which is available online at www.medsmilk.com, or the U.S. National Library of Medicine's free, online guide LactMed, available at https://toxnet.nlm.nih.gov/newtoxnet/lactmed.htm

You can think about medications based on how safe they are to use in pregnancy. Here's how they break down:

Unsafe Medications for Pregnancy:

Cyclophosphamide
Mycophenolate
Methotrexate
Leflunomide

Medications That May Be Safe With Pregnancy:

Hydroxychloroquine
Sulfasalazine
Azathioprine
Tacrolimus/Cyclosporin
TNF-inhibitors
Corticosteroids

Other Medications Often Used in Pregnancy:

Blood thinners
Antihypertensives
Antidepressants

Unknown Safety in Pregnancy, So Generally Avoid:

Rituximab
Actemra®
Orencia®
Xeljanz®
Any other new medications...(because there's not enough data to say one way or the other if they're safe)

Unsafe Medications for Pregnancy

Cyclophosphamide (*Cytoxan®*, *Neosar®*) and **mycophenolate** (*CellCept®*, *Myfortic®*) are two drugs that are sometimes used to treat RA, and very often used to treat lupus. You should not use either of these drugs while you are pregnant or breastfeeding. An estimated 40-50% of pregnancies conceived on either of these medications will result in a pregnancy loss. Of those born alive, one out of four (about 25%) will have a major birth defect, often of the face. For this reason, it is really important to use very effective birth control when you take these medications. If you get pregnant while taking one of these medications, contact your doctor right away. You will need to talk

about your options, which might include terminating your pregnancy.

If you are taking one of these medications but want to get pregnant, talk with your rheumatologist and make a plan to safely transition to pregnancy-compatible medications. Most women with lupus active enough to need cyclophosphamide or mycophenolate would have a severe flare if the medication is simply stopped. Having this kind of severe flare would put both the mother and fetus at very high risk for permanent damage. Therefore, most women will be switched to pregnancy-compatible medications, like azathioprine, tacrolimus, or cyclosporine. Once the cyclophosphamide or mycophenolate has been stopped for 3-6 months and lupus is proving to be well controlled on the pregnancy-compatible medications, then you can proceed to pregnancy.

Methotrexate (*Rheumatrex®, Trexall®, Rasuvo®, Otrexup®*) is not safe in pregnancy and should be stopped three months prior to conception, if possible. You should probably continue taking your daily folic acid for several months after stopping your methotrexate (in addition to taking a prenatal vitamin in preparation for pregnancy). If you are taking methotrexate and think you are pregnant, contact your rheumatologist immediately.

Many years of data show that methotrexate is **teratogenic** – that means it can harm the fetus, and potentially cause deformities, death, and could hinder the baby's growth and the development of its arms and legs.

Early in a pregnancy—when women who have an unplanned pregnancy may not yet realize they are pregnant—methotrexate can cause miscarriage and/or birth defects. At the low weekly doses of methotrexate that rheumatology patients take, the risk of a baby being born with a birth defect after several doses of methotrexate in pregnancy is two- to three-fold higher than the usual rate. In the general population, about 3% of all babies are born with a birth defect; about 7-10% of babies exposed to methotrexate early in pregnancy are born with a birth defect. Prenatal testing, such as amniocentesis, ultrasound or blood tests, may be able to detect birth defects in the baby. Pregnancy loss is a more likely outcome, with up to 40% of pregnancies exposed to methotrexate resulting in a miscarriage or stillbirth.

Leflunomide (*Arava®*) is also contraindicated for use during pregnancy. Data from studies on animals suggested that leflunomide was very dangerous, causing high rates of pregnancy loss and birth defects at low doses. In humans, however, it appears that it isn't as damaging. A study by MotherToBaby, a public service project that's part of the Organization of Teratology Information Specialists (OTIS), showed that women with RA who got pregnant on leflunomide, stopped it when the pregnancy was discovered and took a medication to quickly wash the drug out of their system, had the same frequency of pregnancy loss and birth defects as other women with RA and healthy women. While this data doesn't suggest that leflunomide is safe in pregnancy and should be continued, it does suggest that it isn't as dangerous as we originally thought.

Women who take leflunomide are advised to use effective forms of birth control to prevent pregnancy. If you're taking leflunomide and suspect that you may be pregnant, your rheumatologist will advise you to stop taking the drug and begin an accelerated process to clear it from your system.

It's recommended that women who take leflunomide stop taking the drug for two years before trying to conceive, or that they go through a drug clearing process with their rheumatologist. Women of childbearing age who are concerned about unplanned pregnancies while they are taking leflunomide should talk to their rheumatologist about alternative treatments.

Medications That May Be Safe With Pregnancy

Now that you know the drugs that are not safe to use during pregnancy and/or breastfeeding, what options do you have to treat your symptoms and keep your rheumatic disease activity under control? There are quite a few treatments that are considered safe to use.

However, if you use any medications and suspect an unplanned pregnancy, let your rheumatologist and ob/gyn know right away. Your doctors need to know about all the medicines you take, even if you only use them occasionally. This includes any medicines you take for any reason, including over-the-counter drugs.

Anti-TNF and Other Biologics

Tumor necrosis factor (TNF) inhibitors, also called **anti-TNF biologics**, are a group of drugs that block a protein that plays a role in inflammation in many rheumatic diseases. Anti-TNF drugs are approved to treat RA, PsA and AS.

Drugs like etanercept (*Enbrel*®), adalimumab (*Humira*®), certolizumab pegol (*Cimzia*®), infliximab (*Remicade*®) and golimumab (*Simponi*®*, Simponi Aria*®,) have all been studied during pregnancy and breastfeeding.

Newer biosimilars etanercept-szzs (*Erelzi*®), adalimumab-atto (*Amjevita*®), and infliximab-dyyb (*Inflectra*®). Unlike generic medicines where the active ingredients are identical, biosimilars – by definition – are not likely to be identical to the originator biologic. They are similar, but not the same. Biologics made by different manufacturers differ from the original product and from each other.

Anti-TNF biologics are prescribed to treat moderate to severe RA, psoriatic arthritis and ankylosing spondylitis. They can help control inflammation and lower your disease activity. They can ease joint pain, swelling, redness and stiffness, and help prevent debilitating joint and skin damage. They increase the risk of infections, so you should watch for signs of an infection, such as fever, flulike illness or rash. Let your rheumatologist know immediately if you think you may have an infection.

Anti-TNFs: Risk to Baby? New Research May Ease Fears

Do traces of anti-TNF drugs pass to your fetus or nursing baby? These are powerful drugs that treat inflammation by suppressing the body's immune system. If a pregnant or nursing mom takes a biologic, will the drug also affect the baby?

There is evidence that some of these drugs more than others can cross the placenta, the membrane that acts as a protective barrier between the baby and the mother's circulation. However, use of anti-TNFs has generally been considered safe at least during the first two trimesters of pregnancy and lactation. Not all biologic drugs used to treat RA or other rheumatic diseases have the same risk of "crossing the barrier" to the fetus. The anti-TNF drugs that cross the placenta at a high level should be stopped several months prior to delivery. This allows time for the drug to get out of the mother and the fetus's systems prior to delivery, thus decreasing the immunosuppression caused by the medication in the baby.

Different TNF inhibitors move across the placenta to different degrees based on their molecular structures. Research shows that

Hydroxychloroquine (*Plaquenil*®) is an antimalarial drug used to treat lupus and arthritis. It is considered a safe treatment option during pregnancy. Hydroxychloroquine may even be beneficial for pregnant mothers with lupus, as it helps to control their disease, which can cause pregnancy complications if it's not well-controlled.

Sulfasalazine (*Azulfidine*®) is a sulfa drug used to treat RA, PsA, and AS. Sulfasalazine is considered safe to use during pregnancy and breastfeeding. There is limited evidence that sulfasalazine raises the risk of birth defects. As long as the baby does not have jaundice requiring treatment, sulfasalazine is safe to take while breastfeeding.

Azathioprine (*Imuran*®) is approved to treat RA, is often used to treat lupus, and is also sometimes used in PsA to treat psoriatic skin lesions. There is evidence in human studies that it is a safer option to use during pregnancy and breastfeeding. There are large studies of pregnancies exposed to azathioprine in women with kidney transplants or with inflammatory bowel disease that show good safety for the drug. Taken together, there does not appear to be an increase in birth defects or pregnancy losses. There is a higher rate of preterm birth in these pregnancies, but all of the mothers have an underlying illness that also puts the pregnancy at higher risk already.

For women with a recent history of active lupus, or with active lupus in pregnancy, taking azathioprine every day increases their chances of delivering a healthy baby. Very little

some are actually concentrated in the fetal blood stream at levels that exceed those of the mother. The different molecular structure of one of these drugs prompted two studies (discussed below) to explore these issues more fully.

It's natural for you to be wary of any possible risk of harm to your baby. Why take any drug during your pregnancy if you can help it? You should take the medications that decrease the risk to your baby. When you have a rheumatic disease, sometimes leaving it untreated and going medication-free is actually *more* dangerous to your developing baby than medications. Each parent needs to make an individual decision about continuing treatment for inflammatory arthritis during pregnancy, and work with a rheumatologist and ob/gyn to come up with the best plan to protect both mother and child.

New studies are exploring the concern about your therapy's effects on your baby.

A 2017 study called **CRIB**, or **"A multicenter, postmarketing study evaluating the transfer of Cimzia® from the mother to the infant via the placenta,"** explored how the drug certolizumab pegol (*Cimzia®*), an anti-TNF biologic drug, passes to the fetuses of pregnant moms with chronic, inflammatory diseases. The study measured the concentration of *Cimzia®* in the babies' plasma at birth. CRIB's results were presented at the Digestive Disease Week (DDW) medical conference in May 2017 the European League against Rheumatism (EULAR) scientific meeting in June 2017 and at the American College of Rheumatology (ACR) in November 2017.

The participating mothers in the CRIB study were at 30 weeks or later of their pregnancies, had at least one dose of the drug within 35 days prior to delivery, and were pregnant with single infants. Any mother whose prenatal testing showed evidence of a fetal abnormality or who had taken another drug known to be teratogenic (a risk to fetal health or life) were excluded from this study.

In the end, 14 babies were tested for traces of the azathioprine transfers into breast milk, making it safe to take this medication while nursing a baby.

Cyclosporine (*Neoral®, Sandimmune®, Restasis®, Gengraf®*) is used to treat lupus, RA and psoriasis. It is considered safe to use during pregnancy, and probably safe to use during breastfeeding.

NSAIDs

Nonsteroidal anti-inflammatory drugs (NSAIDs) are used to ease inflammation. NSAIDs like ibuprofen (*Advil®*, *Motrin®*), naproxen sodium (*Aleve®*), indomethacin (*Indocin®*), diclofenac sodium (*Voltaren®*), ketoprofen (*Arudis KT®*), celecoxib (*Celebrex®*) or meloxicam (*Mobic®*) are likely safe to use during pregnancy, although you should not use them in your third trimester. NSAIDs in high doses also are known to impair fertility.

Some studies suggest that taking NSAIDs in the early stages of pregnancy could increase the risk of miscarriage. However, they are considered safe to use in the first two trimesters, with no known risk for low birth weight, congenital birth defects or premature delivery. In the third trimester, there is evidence that NSAIDs could decrease amniotic fluid, which surrounds and protects your baby in the uterus. Some evidence shows that these drugs, if used in the third trimester, might lead to fetal pulmonary hypertension, a serious risk for your unborn baby.

NSAIDs are widely available to treat occasional flares of joint pain, and are a good option to ease your symptoms during the first half of your pregnancy. If you also have minor back pain flares, you might take an NSAID for relief. They are safe to use during breastfeeding.

NOTE ABOUT ASPIRIN: The American College of Obstetrics and Gynecologists (ACOG) now recommend that all women with autoimmune disease, particularly lupus, take a baby aspirin, 81mg, every day in pregnancy. Taking this low dose of aspirin every day has been shown to decrease the risk for preterm birth and preeclampsia. It's important to start this before week 16 of your pregnancy to get this benefit. Higher doses of aspirin are generally not prescribed in pregnancy. For pain, stick to acetaminophen (*Tylenol®*) or other NSAIDs.

drug after birth. CRIB used a highly sensitive assay test that's designed to pick up even small traces of this particular drug. The test found that there were minimal signs of the transfer of this drug from mother to fetus in the third trimester of pregnancy, so there was likely minimal fetal exposure to Cimzia when the mothers took their treatments.

CRIB also measured any health problems among the mothers during pregnancy and labor, and in their infants after birth. Other than one case of arrested labor and one of prolonged labor, the "adverse events" associated with mothers taking this drug during pregnancy were mild to moderate.

In addition, tests given to the babies after delivery did not show any unusual clusters of adverse events or health problems related to the drug in the period of time studied (up to 8 weeks after delivery). The test results were consistent with the drug's safety profile for use during pregnancy.

The CRIB study looked at how this anti-TNF drug may pass to an unborn baby in the placenta. But what about the drug passing through the mother's breast milk to a nursing baby? Moms with inflammatory arthritis may experience a flare after they deliver their babies and when they are adjusting to breastfeeding. Also, many mothers try to breastfeed for months or longer because of nursing's many health benefits for their babies. If you experience a return or flare of your symptoms after you give birth, you will want safe treatments to help you control your disease activity, get symptoms and joint damage under control, and feel well enough to care for your new baby.

Another 2017 study examined the potential risk of passing *Cimzia* through breast milk. The results of the study, **"Minimal to no transfer of Certolizumab Pegol into breast milk: Results From CRADLE, a prospective, postmarketing, multicenter, pharmokinetic study,"** showed that 17 mothers who took the maintenance dose of the drug six weeks after delivery or later did not transfer any unsafe doses of the drug to their new babies. CRADLE's results were presented at

Corticosteroids

Also called glucocorticoids or just "steroids," corticosteroids are a traditional treatment for inflammation. Common corticosteroids used in the treatment of rheumatic diseases include prednisone, prednisolone, cortisone, hydrocortisone, betamethasone and dexamethasone.

Corticosteroids may be used to treat RA, PsA, AS or lupus, but these drugs may be used less often now than in the past due to newer options. Some people may take a short-term oral dose of steroids to ease a flare of inflammation, or have a steroid injection into a sore joint.

Corticosteroids are considered relatively safe to use during pregnancy and breastfeeding. They can relieve symptoms of a flare quickly and should be used at the lowest dose and for the shortest time possible. They do not transfer across the placenta to the fetus at a high level. Some evidence shows a low risk of a fetus developing a cleft lip if the mother takes corticosteroids in the first trimester of pregnancy. Prednisone may also contribute to the risk for preterm labor and fetal growth restrictions.

Corticosteroids do have a lot of possible side effects, and some of these can be serious, especially in pregnancy. These drugs can increase blood pressure and blood sugar, and prompt excessive weight gain. High blood pressure, diabetes (high blood sugar) and obesity all increase the risk for pregnancy loss, preterm birth, and c-section deliveries. Beyond pregnancy, they can cause glaucoma (increased eye pressure) or cataracts and cause problems with your mood or memory.

You can work with both your rheumatologist and your ob/gyn to monitor any side effects you have with corticosteroids during pregnancy. Your doctors and nurses can go over the possible side effects of these drugs, and what warning signs to watch for, such as new headaches or excessive urination.

Other Medications Often Used in Pregnancy

Your doctors may prescribe of these medications for you during pregnancy. Not every woman with a rheumatic disease will need them, but in some cases, they can be helpful at controlling complications like blood clots or depression.

Blood thinners like heparin and warfarin may be needed by women who have a history of blood clots. Heparin and low-molecular weight heparin are safe to take during pregnancy

the American College of Rheumatology scientific meeting in San Francisco in November 2016.

The mothers had either RA, PsA, AS or Crohn's disease, an autoimmune, inflammatory disease that affects the gastrointestinal system. The study used a sensitive test to measure traces of *Cimzia®* in breast milk. The dose of *Cimzia®* ingested by infants per day through breastmilk was far less than 1 mg; in contrast, the mothers of these infants were receiving either 200- or 400-mg doses of *Cimzia®*. Experts generally believe that there is less reason for concern when infants ingest less than 10% of their mothers' drug doses through breastmilk. In this study, infants only ingested 0.125% of their mothers' doses on average. More importantly, the study showed that any adverse events experience by these babies would be expected in babies whose mothers did not take the drug. ✷

or breastfeeding. Warfarin should be avoided during pregnancy, but is safe to take after delivery and while breastfeeding

Antihypertensives are drugs used to manage high blood pressure, or hypertension. High blood pressure can be a serious concern during pregnancy. Antihypertensive medications that are considered safe to use in pregnancy include methyldopa (*Aldomet®, Aldoril®, Dopamet®*), labetalol (*Normodyne®, Trandate®*), beta blockers (other than one called atenolol) and slow-release nifedipine (*Procardia XL*), and also diuretics if you had hypertension before pregnancy.

However, you should not use angiotensin-converting enzyme (ACE) inhibitors or angiotensin II receptor blockers during pregnancy. Other antihypertensives to avoid during pregnancy are direct renin inhibitors and spironolactone.

Fish oil supplements are also not recommended to use during pregnancy. You may think any "natural" treatment or supplement is OK to take when you're pregnant, but that isn't the case. Tell your ob/gyn if you take any supplements or herbal treatments for any reason.

Antidepressants: According to the March of Dimes, about one in eight pregnant women take an antidepressant during their pregnancy. You may have been taking an antidepressant for a while before getting pregnant, and don't wish to stop it and have depression symptoms return.

There are several types of antidepressants: selective serotonin reuptake inhibitors (SSRIs), serotonin and norepinephrine reuptake inhibitors (SNRIs), trycyclic and tetracyclic antidepressants, and buproprion.

SSRIs are widely used treatments for depression. But there has been conflicting evidence about their safety for use during pregnancy. The Centers of Disease Control and Prevention (CDC) did a major study on this subject in 2015. Their findings showed that one SSRI, sertraline (*Zoloft®*), was the safest, with no confirmed links to serious birth defects. However, they did find evidence that two other commonly used antidepressants, fluoxetine (*Prozac®*) and paroxetine (*Paxil®*), were linked to a risk of some birth defects. The CDC study also concluded that while some SSRIs are linked to a higher risk of certain birth defects, the overall risk was still very low. So talk with your ob/gyn about safe antidepressants to use while you're pregnant.

Unknown Safety in Pregnancy, So Generally Avoid

There is simply a lack of evidence about how safe some drugs used to treat rheumatic diseases are for use during pregnancy. So it's wise to avoid them during this time. Talk to your rheumatologist about any of your questions or concerns about switching to a different treatment.

Rituximab (*Rituxan®*) is a biologic drug that targets B cells that have the protein CD-20 on their surfaces. These B cells play a role in inflammation in some rheumatic diseases. Rituximab is approved for use in RA, as well as two types of vasculitis: granulomatosis with polyangiitis (GPA) and microscopic polyangiitis (MPA).

There is a lack of evidence to show that rituximab is safe to use during pregnancy, and some evidence shows that it may increase the risk of lymphocytopenia in fetuses. It isn't the right choice for most women in pregnancy, but

can be used in rare cases under the direction of a rheumatologist.

Tocilizumab (*Actemra*®) is a newer biologic called a monoclonal antibody. It is approved to treat RA either alone or in combination with methotrexate or another DMARD. There is very little data on human pregnancies, so it is best to avoid this drug during pregnancy and switch to medications that have been shown to be compatible with pregnancy, like TNF-inhibitors.

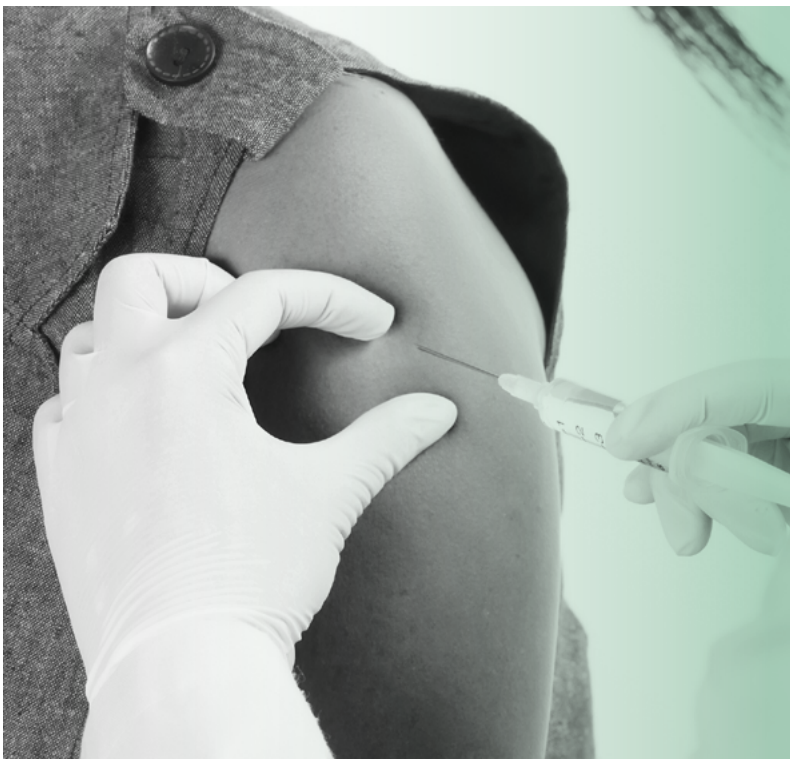
Abatacept (*Orencia*®) is a biologic called a T-cell blocker. It is approved to treat moderate to severe RA and psoriatic arthritis either alone or in combination with anti-TNF biologics. There isn't enough evidence to show whether abatacept causes any risks to an unborn baby or the mother during pregnancy.

Anakinra (*Kineret*®) is a biologic called an interleukin-1 receptor antagonist. Anakinra is used to treat RA if one or more DMARDs haven't worked. There is little evidence about whether or not its use during pregnancy affects the fetus' health or development.

Secukinumab (*Cosentyx*®) is a biologic that targets and blocks a protein called interleukin-17a, which plays a role in inflammation. It is approved to treat PsA and AS. There are no adequate, well-controlled studies on the safety of secukinumab's use during pregnancy.

Tofacitinib (*Xeljanz*®) is a newer type of biologic drug called a Janus kinase inhibitor, and is approved to treat RA. The pregnancies studied after exposure to tofacitinib do not reveal worrisome problems, but there are very few of them and they haven't been studied systematically. For not, you should avoid pregnancy while taking tofacitinib. The drug's manufacturer currently has a registry to collect data and monitor its safety when used during pregnancy and breastfeeding.

Ustekinumab (*Stelara*®) is a monoclonal antibody that blocks interleukins 12 and 23. It is approved to treat PsA. There is not enough evidence on its safety for use during pregnancy. The only limited information on ustekinumab's use in humans during pregnancy is what are called limited observational studies. These studies are small, and do not use controls to thoroughly evaluate the drug's effects. You and your rheumatologist can talk about whether or not you should continue to use ustekinumab during your pregnancy if you have active PsA. The drug's manufacturer has a pregnancy registry to collect more data on its safety.



New Medications:
New treatments for rheumatic diseases are in the pipeline, and may be approved at any time. These treatments may provide new options to control inflammation and disease activity, but we don't know how safe they will be to use during pregnancy. It takes a long time to fully study the effects of medications on a fetus or pregnant mother, so your rheumatologist will want you to keep using treatments that are known to be safe.

PART SEVEN

I'm Pregnant...Now What? How Arthritis May Affect Pregnancy

As we have discussed earlier in this guide, your arthritis symptoms may lighten up during pregnancy, especially if you have RA. But also know many women may experience worsening symptoms or disease flares during pregnancy, particularly if medications have been stopped. Everyone is unique. Women with any rheumatic disease could have a flare during pregnancy, so let your rheumatologist and ob/gyn know if you notice any symptoms.

However, the normal—if unpleasant and inconvenient—symptoms of pregnancy may mimic arthritis symptoms, and can even make some joint and muscle problems feel worse.

- Joint pain and pressure on joints may increase. As you gain weight during pregnancy or retain more fluid, joints like your knees, ankles and feet may ache due to this increased pressure. You may notice joint pain when you walk up and down the stairs or move around.
- Water weight gain can make your lower extremities swell too, such as your lower legs, ankles or feet. If you notice any severe swelling, tell your doctor right away.
- As your baby grows, your uterus expands with it. This can put pressure on your spine and back. You may notice back pain, back muscle spasms, or numbness and tingling in your legs.
- The muscles you use to breathe push upward as your baby grows in your uterus. You may notice shortness of breath at times. Talk to your rheumatologist or ob/gyn if you are concerned about shortness of breath or dizziness.
- You will gain weight during your pregnancy. This can put extra pressure on joints that your arthritis has damaged or weakened. Try to keep your weight gain in the range that your obstetrician has recommended, usually around 20-30 pounds if you start out in the 'normal' weight range. If you are overweight or obese, talk with your ob/gyn about how much weight you should gain in pregnancy for optimal health. Eat a healthy diet that will nourish both you and your baby.
- Many women experience constipation or other bowel problems during pregnancy. If this happens to you, talk to your doctor. You may be able to take treatments to improve regularity, or change your diet to ease these symptoms. High-fiber foods, plenty of water and regular exercise are healthy ways to promote regularity.
- Weight gain and other normal aspects of pregnancy can make you feel sluggish and tired. Make sure that you stick to the physical activity plan that your doctors give you. Your rheumatologist and ob/gyn can create a safe, healthy exercise plan for you to follow during your pregnancy. They can also refer you to pregnancy exercise classes or therapists that can guide your physical activities.
- Use the same joint protection techniques you always use to prevent pain and injuries: range-of-motion exercises, good posture, hot or cold packs on sore joints, splints or assistive devices if you need support, and good sleep habits. Wear comfortable, supportive footwear to prevent slips or falls.

A note on your mental well-being:
It's also normal during pregnancy to feel irritated, anxious, tired or stressed out. Being pregnant and having a chronic rheumatic disease, with extra medical appointments, tests or concerns, can put a strain on your emotions too. If you feel overwhelmed, talk to your doctors. They may be able to answer questions you have so you feel less confused or scared. They can also refer you to mental-health services or counseling if you need it. Many couples attend prenatal support groups to share their questions or concerns with others in their situation. This can help you relax a bit, because you know that you're not alone and your concerns are normal.

PART EIGHT

The Big Day: Labor & Delivery

While all pregnant women hope for a smooth delivery, that isn't always possible. It is important to keep in mind the most important goal: a healthy baby and healthy mother. For many women, this means a vaginal delivery. But for others, and about half of women with lupus, a cesarean delivery is required to ensure the healthiest baby possible. The rate of vaginal delivery versus cesarean delivery is about the same among women with rheumatic disease as the general population. It isn't "your fault" if you are unable to have a vaginal delivery for any reason.

If your arthritis has caused any joint damage in your hips or lower back, or if you have a rheumatic disease like AS that can cause inflammation in your lower spine, labor could be more difficult. Toward the end of your pregnancy, talk with your rheumatologist and ob/gyn about what you should expect during your labor. Talk about your particular joint problems and your options, including physical therapy, to manage pain during this time.

Most women with arthritis can deliver their babies lying on their backs, or a normal vaginal delivery. If this position causes you additional pain due to your arthritis, you may be able to deliver the baby while lying on your side or in a special birthing chair. Talk to your ob/gyn or midwife about your options for delivery. You will also work with an anesthesiologist to choose pain management strategies if you choose any during labor.

Some women, including those with or without a rheumatic disease, sometimes need to deliver their baby through a cesarean section. This is a surgical procedure that involves an incision through the mother's abdomen and uterus to deliver the baby. Women with hip joint damage due to their arthritis could plan for a c-section delivery prior to going into labor. Talk with your ob/gyn about your options for delivery that take your joint damage into account.

During your labor and delivery, your obstetrician will also monitor your baby's health to look for any signs of distress during this time. Mothers with lupus, antiphospholipid syndrome and some other rheumatic diseases may be at risk for placenta problems during pregnancy. Careful monitoring during your labor helps your obstetrician detect any problems in case you need to have a c-section to ensure a safe delivery.

The Koebner phenomenon:
Women with psoriasis can have a flare of skin inflammation around the incision of their cesarean section, or on other places of their body after this type of incision. These flare-ups of psoriasis are called the "Koebner phenomenon," and they can occur after any type of skin injury or puncture, even after a tattoo or piercing. Talk to your obstetrician if you are concerned about reactions from your c-section incision.

PART NINE

Post-Delivery: Treating Flares & Caring For Your New Baby

Parenting

Taking care of a newborn can be exhausting and physically taxing for anyone. New parents with a rheumatic disease may have even more challenges with the lack of sleep, feedings every two hours or so, lifting an infant for dressing or diaper changes, bathing the infant, and other everyday parenting tasks. If your disease flares after delivery, pain, joint swelling or stiffness, fatigue and other symptoms may make these tasks very hard to do.

After delivery and recovery, you and your new baby will go home to begin your new life together. Caring for a newborn is both exciting and tiring for just about every new parent! Newborn babies wake up, cry, and need diaper changes, cuddling and feeding every few hours. It can be very hard for new parents to get any sleep.

As we have discussed earlier in this guide, some rheumatic diseases may flare one to six months after delivery. Before the routine use of medications, about 75% of new mothers with RA experience a flare within three months after their delivery. This may be the last thing you want to experience as you are trying to care for your newborn. Even with help from your partner, friends and family, or a home health aide, caring for a new baby means lifting, carrying, stooping, bending, changing diapers, holding the baby during feedings, bathing and other physically taxing tasks.

To avoid having a post-partum flare, your rheumatologist will go over your options to resume disease-modifying medications within a few weeks of your delivery. Treatments can ease inflammation and get your flare under control. However, you may be concerned about whether or not your treatments are safe to take during lactation, or breastfeeding.

Almost all treatments for rheumatic diseases are safe to use while you are breastfeeding. Your rheumatologist should be able to create a treatment plan for you that will not put your baby at risk. As we discussed earlier in this guide, every drug has its own risk profile for use during either pregnancy or lactation.

Here is a quick breakdown of rheumatic disease treatments that are considered safe to use during breastfeeding:

- **NSAIDs:** All except aspirin
- **Corticosteroids**
- **Acetaminophen** (*Tylenol®*)
- **Hydroxychloroquine**
- **Sulfasalazine**
- **Azathioprine**
- **Tacrolimus or Cyclosporine**
- **TNF-inhibitor biologics**
- **Heparin and warfarin**

These rheumatic disease treatments may not be safe to use during lactation because there isn't enough data to tell us about transfer into breast milk:

- **Methotrexate**
- **Mycophenolate**
- **Cyclophosphamide**
- **Leflunomide**

These treatments may be safe to use during lactation, although there isn't enough evidence yet to be sure. Because they are large molecule biologics, it is unlikely that they will pass through the maternal blood barrier into the breast milk. Talk with your rheumatologist about the risks and benefits of taking these drugs while you are breastfeeding, and if you have any other options:

- **Rituximab**
- **Secukinumab**
- **Tocilizumab**
- **Tofacitinib**
- **Ustekinumab**

CARING FOR YOUR NEWBORN: ASK FOR HELP! Caring for a new baby is exhausting and physically taxing for all moms and dads. If you or your partner has a rheumatic disease, it can be even tougher on your body and health.

Ask for help! Don't wait until you are about to collapse from joint pain, exhausting fatigue, muscle weakness or stiffness, or other severe symptoms. If you are having a flare soon after your delivery, you will need help caring for your baby. Don't feel ashamed to ask for help from family or friends with even the most basic or minor tasks.

Here are a few tips to keep in mind:

Muster the troops: Set up a plan for post-delivery assistance in the final weeks of your pregnancy. See if relatives or friends can stay with you for a little while after you come home with your baby, or be "on call" to come over on short notice if you are struggling with baby care tasks like bathing or feeding. People who love you want to help you.

Keep phone numbers handy: Program the contact information for family members, friends, doctors or services into your phone so they are easy to find when you need help.

Use assistive devices or modifications: There are tons of tools and gadgets to make caring for your baby easier on your joints. These can be as simple as bathing basins with plugs you can drain right into the sink instead of carrying it full of water, wash mitts so you don't have to grasp a washcloth or sponge, and dressing your baby in clothes that fasten with Velcro so you don't have to fuss with buttons or snaps. Check online to find what you need to make these tasks easier. There are also aids to help support your baby while you breastfeed or bottle-feed – babies can be heavy to hold and put a strain on weak joints.

Do what you can and then let others take over: Don't feel guilty if you're not able to do everything involved in caring for your new baby. It's OK to let others share tasks like feeding from a bottle, bathing your baby, watching your baby while you take a nap, doing laundry or cleaning up dirty diapers.

Explore outside help: If your budget accommodates a hired professional, this can be a huge help for you as you care for your newborn. Nannies, au pairs, home health aides and other assistants can come to your home for short periods of time or stay with you around the clock.

For arthritis specific information, the Canadian Arthritis Patient Alliance created a full resource on helpful tips. You can find it here: http://www.arthritispatient.ca/information-resources/pregnancy-parenting

Feeding Your Baby: Choosing the Right Option For You

Earlier in this report, we discussed the possible risks of taking some arthritis drugs when you're breastfeeding. There are many treatment options that are safe for you to use to control your rheumatic disease in the weeks and months after delivery.

There are other things to consider when you're making the choice to breastfeed or not. This is a personal decision for you and your partner to make. You can talk with your physician or your baby's pediatrician about any concerns or questions you have about breastfeeding, and other options you have if you choose not to breastfeed. Some moms choose to pump their breast milk and feed their new babies by bottle, or use formula that is fed to the baby in a bottle. Some moms may try breastfeeding for a period of time, and then switch to formula later.

It's up to you to decide how to feed your baby. When you have a rheumatic disease like RA, PsA, lupus or AS, you may have joint pain or damage that makes it hard to hold your baby as he or she feeds several times of day and night. If you're having a flare, you may not feel up to breastfeeding during that time.

However, there's no reason why new mothers who have rheumatic diseases can't breastfeed as long as they're not taking any medications that could be harmful to the baby. Talk with your rheumatologist about any concerns or questions you have about breastfeeding while you take any medications.

Why is breastfeeding a good idea?

- Breast milk is a safe, natural food for your baby. It contains healthy antibodies and hormones that help your baby build up its immune system.
- Colostrum, the thick, yellowish fluid you produce in your breasts at the start of nursing, contains nutrients that help your baby fight off infections.
- Research shows that breastfeeding your baby your own milk can reduce your baby's risk of developing health problems like asthma, diarrhea, ear infections, eczema, lower respiratory infections, SIDS, some pediatric cancers, and type-2 diabetes.
- Children who were breastfed are less likely to be obese.
- Breast milk may also reduce the risk of certain childhood cancers like leukemia, and maternal cancers such as uterine, ovarian, and breast cancer.
- Breastfeeding may also help nursing mothers lower their risk of diabetes and certain cancers. It may also help you lose weight after giving birth because it burns calories.
- Breastfeeding helps mothers by reducing the risk of postpartum hemorrhage. When you breastfeed, your body produces hormones that cause uterine contractions, encouraging it to return to its normal size. This prevents hemorrhage in the first few days to weeks after childbirth.

There are psychological benefits to breastfeeding too. According to the American Academy of Pediatrics' "New Mother's Guide to Breastfeeding: 2nd Edition" published in 2015, the act of breastfeeding—holding your baby close to your body—can make your new baby feel safe and protected. You also release hormones during breastfeeding that nurture your bond with your baby – a "mothering instinct."

If you choose to bottle-feed your new baby, you can also develop a bond with your baby and nurture it. Don't stress out over any decision you make or if you decide to stop breastfeeding at any point. Your baby can grow up healthy, loved and well developed no matter how you choose to feed it during infancy.

If you decide to breastfeed, here are some tips to keep in mind as you nurse:

- Find a comfortable position for breastfeeding. Support your back and neck by sitting in a solid chair or up in bed against a headboard. If you have a chair that lets you lean back a little, this can help you get in the right angle.
- Rest your feet on something like a pillow, footstool or cushion.
- Make sure your arms are supported as you hold your baby during feeding. There are lap cushions and other devices that are designed to help you support your baby's head and body.
- Some moms choose to breastfeed while lying on their sides, and use a cushion or pillow to support the baby.
- If your arthritis has damaged your upper body joints, you may need help from another person or nursing device or cushion. Make sure you don't injure your joints just because you feel that you're "supposed to" do everything yourself.
- Soon, you may need or want to nurse your baby outside the house. You will want to go out to run errands, go to your or your baby's medical appointments, visit friends and family, go out to dinner or shop. To make it easier on you, limit the amount of paraphernalia you carry with you in your diaper bag as much as you can. Or split the items up between you and your partner if you're both going out together. Breastfeeding does require fewer things to carry, but you may want to take a sling or cushion with you if you need it on the go.

Some new moms have trouble breastfeeding. It happens to moms who don't have a rheumatic disease too. Your doctor can refer you to a lactation consultant if you need one. These professionals can help you work through issues with breastfeeding.

Formula or "Bottle" Feeding

If you find that you don't wish to breastfeed, cannot breastfeed or need to stop at some point, there are alternative feeding options. You can, of course, switch to formula to feed your baby. Do not worry that formula feeding will harm your baby. It will not. High-quality formulas are available to feed babies that give them every nutrient they need to grow and develop healthfully. There are also supplements made from human milk that you can add to your baby's formula that make it even better for your child.

If you cannot or don't want to breastfeed but don't feel formula is best for you, there are multiple services where you can purchase breast milk for your baby. There are milk banks in each state with donated breast milk that is checked and processed to ensure it is safe for your baby. You can speak with your pediatrician, ob/gyn, or a lactation consultant about the best way to get information about this process.

As you hold and feed your baby with a bottle, you can bond and connect just as you would while breastfeeding. Your baby will feel safe, nurtured and loved.

The most important thing to remember is to **adapt feeding to your needs.** If your arthritis affects certain joints like your neck, back, shoulders or upper arms, look for new positions or supportive devices to help you adapt. Some people with RA have severe joint pain or stiffness in their hands that may make holding a baby bottle for a long period of time difficult or impossible. PsA can cause severely swollen, "sausage" fingers or painful nail damage that may make it hard to hold a bottle too.

If you have any trouble holding your baby or their bottle, see if you can find devices to help you. Grippers could fit around a baby bottle to make it easier to grasp. Slings can fit around your upper body to help you hold your baby in

place. Or, ask for help. Your partner can and should help you feed the baby. You don't have to go it alone.

Diapering, Dressing and Other Baby Care Tasks

Taking care of a new baby means no end of things to do: diaper changes, cleaning and bathing, dressing your baby, laundry, changing the crib sheets, locking and carrying the car seat, and a very long list of other tasks. Moms and dads with rheumatic diseases have the same responsibilities as other new parents, but may also have to deal with joint pain, stiffness or damage, limited mobility, or fatigue and flares.

Talk with your rheumatologist quickly if baby care tasks become too difficult for you to do. Don't allow yourself to feel like you're letting your baby or partner down. Your doctor may be able to adjust your treatment so you control your disease more effectively and feel better. Your rheumatologist can also refer you to physical or occupational therapy – these healthcare professionals can help you adapt your movements or find assistive devices that make it easier for you to care for your baby.

Here are a few tips for common baby care tasks if your arthritis makes them harder or more painful to do:

- If your baby moves around a lot when you're trying to clean or diaper him or her, place a toy nearby for a distraction – or sing a little song and make eye contact.
- As your baby gets a little older, you may be able to teach him or her to lift up a little during diaper changes. Children who are one month or older may be able to lift their bottoms up a bit, making it easier for you to change the diaper.
- Make a duplicate diaper bag or set of supplies to keep on hand when you're on a different floor of your house. This can cut down on the need to transport your baby to another part of the house just for a diaper change or clean-up.
- When you lift your baby, use your arms, not just your hands. Your hand joints are small and could be weakened by arthritis. You have stronger muscles in your arms and shoulders.
- If you use any diaper creams or similar products, try to find brands in easy-to-open containers with large lids. These can put less strain on your hands, as well as not causing you to stress out because you can't open the jar! Baby wipes also come in containers with easy to open lids.
- Dressing a baby can be frustrating for moms and dads who don't have arthritis! Try to find baby outfits with easy fasteners like Velcro, zippers, and magnets rather than buttons or snaps. Anything that can be easily changed is best. Also, look for clothes in fabrics that are easy to care for and laundered, and don't need to be ironed. Your baby will never know that you don't like to iron!
- For bathing, check out baby tubs that can be easily filled and drained in the tub or sink. You don't have to lift these tubs when they're full of water. Ask for help if you cannot lift your baby into a bath. Sponge baths or wipes are another way to keep your baby clean, or attend to unexpected messes, without a full bath.
- Look for "baby-shaped" sponges that support your baby while he or she is in the bathtub.
- When you and your baby are on the go, use lightweight strollers that you can easily transport, collapse and put in the car. Test different strollers in the store before you buy them. Make sure you can easily put the rain cover in place and remove it, lift the stroller, get your baby in and out of the stroller, and other important tasks.

Post-Partum Depression: Seek Help If You Need It

Many new mothers are susceptible to post-partum depression. This is a serious medical condition that may require treatment, so speak to your physician if you show any signs of depression after you and your baby come home.

Your rheumatic disease could put you at risk for depression after you have a baby. You may have a flare that causes severe pain or lack of mobility, making it hard to care for your new baby. You may worry about your ability to take care of your baby as he or she grows up. Getting little or no sleep could just make you feel more fatigued and moody. You may find that you have so many responsibilities because of caring for a new baby that you feel lost, confused or sad.

If you notice the signs of depression, or if others around you notice something is wrong, speak up. Don't deal with it alone.

Your doctor can refer you to treatment for depression. You may find that counseling or other therapy can help you cope with your post-partum depression. Your doctors, nurses and therapists can also suggest ways to adapt to your new role as a parent, and help you find ways to balance your responsibilities and your rheumatic disease's physical challenges.

PART TEN

Healthy Pregnancy, Healthy Baby, Healthy Mom: Tips to Keep in Mind

The good news is that you *can* have a very healthy, normal pregnancy with a rheumatic disease. You can have a normal delivery and a healthy, active, happy baby. You can nurse and care for your baby just like any other parent does, and adapt every task to your needs and physical condition.

Every day, moms and dads with rheumatic diseases like RA, PsA, AS and lupus start their own families. These diseases do not need to limit you when it comes to conceiving, having a healthy pregnancy and raising your kids.

Keep these tips in mind as you plan to start your family:

Work with your rheumatologist, ob/gyn and other physicians on your healthcare team to talk through any problems or concerns, or to find the treatments that work best for you.

Plan ahead for pregnancy if you can. Talk to your rheumatologist before you try to conceive. Use birth control until your rheumatologist gives you the all-clear sign to begin trying to get pregnant.

Let your rheumatologist know as soon as you confirm your or your partner's pregnancy. If tests need to be done, it's good to notify your doctor as soon as possible.

Ask for help when you need it. Let your family and friends know ahead of time that you may need to call on them for help with tasks like driving or carrying, or feeding, diapering or bathing your baby. Keep contact info for your "support network" programmed into your phone. If you can, arrange for a home health aide for the first few weeks after delivery.

Get support from other parents with rheumatic diseases. Check out volunteer groups in your community, or go online on sites like CreakyJoints.org or disease-specific foundations. Ask questions. Get tips from other parents. Share your experiences with them too.

Enjoy this special time! If you have any questions or concerns about how to ensure a healthy, safe pregnancy and baby, talk to your physicians. Remember to relax and enjoy being a new parent. Let everyone else make a fuss over you just a little bit. Enjoy creating your baby's nursery or a web page about your new baby for family and friends to visit.

This is a very special time in your life. Celebrate the joy of your new baby and life as a parent!

About the Reviewers

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Dr. Clowse is an Associate Professor of Medicine in the Division of Rheumatology & Immunology at Duke University in Durham, North Carolina. She is the director of the Duke Autoimmunity in Pregnancy Clinic and Registry and has dedicated her career to assisting women with rheumatic disease build the families that they desire. She is an international leader in the field, teaching physicians about how to manage rheumatic disease in pregnancy through lectures, studies, and chapters in leading rheumatology textbooks.

CANADIAN ARTHRITIS PATIENT ALLIANCE

Canadian Arthritis Patient Alliance (CAPA) is a grass-root, patient-driven, independent, national organization with members across Canada and supporters both Canadian and International. CAPA believes the first expert on arthritis is the individual who has the disease and theirs is a unique perspective. They advocate on range of health policy issues including patient involvement in research, federal drug regulation, drug funding decisions, and many other issues that affect the daily lives of people living with arthritis. CAPA has developed a number of resources for people living with arthritis including a pregnancy and parenting resource, biosimilars video and a resource on pairing biologics and Methotrexate. Learn more by visiting the CAPA website at www.arthritispatient.ca.

RACHELLE CROW HERCHER, M.ED

Rachelle is a former special educator turned stay at home mom who has spent the past six years championing for complete, easily-accessible information for patients living with rheumatic diseases who wish to become parents. Upon having her first child, she realized that there was no consistent, patient-friendly resource to reference for medication use and disease management during pregnancy and breastfeeding. She has continued to champion for a patient-centered approach to treating rheumatic disease in patients during their reproductive years and providing each patient with clear, concise information to help decide their treatment path. In addition to parenting her two daughters, she has also served as a patient governor for Arthritis Power, including serving one year as the Chair of the Patient Governor Group.

These patient guidelines for pregnancy and family planning were made possible through the generous support of UCB, Inc., a global biopharmaceutical company with U.S. headquarters in Smyrna, Georgia.

Glossary

A

Abstinence – refraining from sexual intercourse.

Amniocentesis – a procedure when a needle is inserted through the abdominal wall of the woman in order to obtain a sample of amniotic fluid. This is done to diagnose genetic defects or possible complications.

Amniotic Fluid – the fluid that surrounds the fetus during pregnancy to help the baby move within the womb, allow lungs to develop properly, maintain an appropriate temperature, and protect the baby from outside injury.

Antiphospholipid Syndrome – a condition that causes your immune system to attack normal blood proteins, leading to blood clots. It may cause complications in pregnancy, including miscarriage and stillbirth.

Antiphospholipid Antibody Test – a test done via blood draw to measure for the antibodies, or proteins used by your immune system, that are present in Antiphospholipid Syndrome. This is to help with diagnosis.

Anti-DNA Antibody Tests – a test done to measure for antibodies, or proteins used by your immune system, that are present in Lupus. This is done to help with diagnosis.

Anti-La/SSA antibodies and anti-Ro/SSA – These are found in people with systemic lupus and primary Sjogren's syndrome. They may also be found in systemic sclerosis, rheumatoid arthritis, and polymyositis. Babies of mothers with these are at an increased risk for neonatal lupus.

Assisted reproductive technology (ART) – all fertility treatments in which both eggs and embryos are handled. This usually involves surgically removing eggs, combining them with sperm in the laboratory, and placing them within a woman's body**.**

Average Daily Infant Dose (ADID) – the average amount of drug prescribed to a mother that is passed to an infant through breastmilk over the course of one day. Usually expressed as milligrams per kilogram per day (mg/kg/d)**.**

B

Blood thinner – a drug used to prevent the formation of blood clots by preventing the coagulation of blood.

C

Cervical Cap – a silicone cup placed inside the vagina to cover the cervix, preventing sperm from joining an egg.

Cesarean delivery (c-section) – the delivery of a baby through incisions made in the mother's abdomen and uterus.

Colostrum – the first fluid that comes from the breast after giving birth. It is rich in antibodies that help the infant.

Complement tests (C3 and C4) – a blood test done to measure the activity of key proteins in your body's immune system. This is done to measure the efficacy of treatments. It can also be done to predict likelihood of a repeat miscarriage. In women who have had miscarriages, C3 and C4 levels were higher in those who had additional miscarriages than in those who had a live birth. Low complement levels are seen in active lupus.

Glossary

Complete Blood Count – a blood test used to measure your overall health and detect all features of your blood.

Conception – the process of becoming pregnant.

Conceive – to become pregnant.

Congenital Heart Block – A problem in which the electrical currents of the heart are slowed or disrupted, resulting in irregular rates or rhythms.

Contraception – the prevention of pregnancy through use of medications, techniques, or devices.

Cytokine – proteins that are released on contact with a specific antigen, they generate the immune response.

D

Diaphragm – a thin, dome shaped device worn over the cervix to prevent pregnancy.

E

Echocardiogram – an ultrasound image of the heart that shows size, motion, and structure. It is used to diagnose abnormalities of the heart.

Entheses – where tendons or ligament attaches to bone.

Epidural – an injection into the spine that anesthetizes all tissue distal to, or below, the injection site.

F

Fatigue – physical and/or mental exhaustion.

Fertility – the ability to conceive or reproduce.

Flare – a rise in disease activity marked by worsening of symptoms.

G

Genetic testing – a test to determine if a person has or will develop certain diseases, or could pass those on to their children.

Gestation – the gestational period is the duration of pregnancy where the growth and development of the fetus occurs.

Gestational Diabetes – a condition that occurs to a mother during pregnancy wherein defects involving the way the body processes and uses sugar occurs.

H

HELLP Syndrome – a form of severe preeclampsia. The letters stand for Hemolysis, Elevated Liver function, and Low Platelet levels.

HLA-B27 – a protein marker on cells that may indicate ankylosing spondylitis.

Hypertension – high blood pressure.

Glossary

I

Inflammation – your body's response to injury or destruction of tissues, it can be localized or systemic, and it involves heat, redness, swelling, pain, and loss of function**.**

Intrauterine device – a mechanical device inserted into the uterus for the purpose of preventing pregnancy. They can be metal or plastic, include hormones or not.

Intrauterine growth restriction – fetal weight that is below the 10th percentile for gestational age.

In Vitro Fertilization – a series of procedures used to treat fertility or genetic problems to help with the conception of a child.

K

Koebner Phenomenon – the formation of psoriasis on an area of skin after cutaneous trauma, such as a cut or injury.

L

Labor – the process of childbirth.

Lactation – the secretion or formation of milk.

Lactation Consultant – a professional trained to solve problems and help with women who wish to breastfeed.

M

Miscarriage – the delivery of a fetus before it has developed enough to survive independently, spontaneously or as the result of an accident**.**

N

Neonatal Lupus – a rare autoimmune disorder present at birth. Infants often have a red rash, congenital heart block, liver disease, low platelets, and low white or red blood cells. Separate from systemic lupus erythematosus.

O

Obstetrician – a doctor who deals with childbirth and caring for women.

Ob/Gyn – an Obstetrician and Gynecologist, who treats all areas of women's health.

Ovulation induction therapy – hormone therapy used to stimulate release of an egg.

P

Placenta – a temporary, disk shaped, organ that joins the mother and fetus to transfer oxygen and nutrients from the mother and allowing for the release of carbon dioxide and waste products from the fetus.

Polycystic Ovarian Syndrome – a problem in which a woman's hormones are out of balance, causing issues with periods, fertility, and physical changes.

Post-partum – the period after childbirth.

Glossary

Post-partum Depression – a severe form of depression lasting more than two weeks after childbirth which may include mood swings, crying, anxiety, fatigue, difficulty sleeping, and other mood changes.

Post-partum hemorrhage – when a woman experiences heavy bleeding after childbirth, which may be life threatening. Usually occurs within the first day, but may occur up to 12 weeks after having a baby.

Preeclampsia – a condition that may occur during or after pregnancy and can affect both mother and baby. It is rapidly progression and includes high blood pressure, headaches, protein in the urine, swelling, vision changes, difficulty breathing, and may result in seizures or HELLP syndrome.

Prenatal Vitamins – vitamins and supplements that are intended to be taken before and during pregnancy and lactation.

Preterm Birth – when a baby is born before 37 weeks of pregnancy.

R

Remission – a period when disease activities and symptoms reduce to the point of going away altogether.

Rheumatic Disease – a disease that attacks your joints, muscles, and immune system.

Rheumatologist – a doctor who has special training in the diagnosis and treatment of musculoskeletal disease and autoimmune conditions.

S

SIDS – sudden infant death syndrome is the unexplained death (usually during sleep) of a seemingly healthy baby less than a year old.

Sperm count – the number of active sperm produced by a man's body.

Still Birth – the death or loss of an infant before or during delivery, usually after 20 weeks of pregnancy.

T

Teratogenic – toxic for an embryo, can disturb development, produce a malformation, or halt a pregnancy.

U

Ultrasound – a tool that forms a two dimensional image to examine and measure an internal body structure or fetus .

Urinalysis – the chemical analysis of urine.

Uterus – a muscular organ in a female abdomen which contains the fetus while it develops.

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