Insurance Toolkit

for
Juvenile Idiopathic Arthritis patients and families

Prepared by the PR-COIN Parent Working Group

PEDIATRIC RHEUMATOLOGY PR-COIN CARE & OUTCOMES IMPROVEMENT NETWORK

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ABOUT THIS TOOLKIT

Understanding your health insurance plan is very important when living with a chronic health condition such as juvenile idiopathic arthritis (JIA). This toolkit was created to explain the basics of health insurance coverage and give you the tools to better advocate for yourself/your child while seeking coverage for tests and treatments.

This toolkit was not created to help you pick a health plan. If you need help selecting a plan, please see the Arthritis Foundation resources (www.arthritis.org/rx-for-access). You can also find information on HealthCare.gov and on the site for your state's Consumer Assistance Program (www.cms.gov/CCIIO/Resources/Consumer-Assistance-Grants).

INSURANCE PLANS

Government Regulation

Some health plans are regulated by state laws while others are regulated by federal laws. This can be confusing, especially when a state or federal government passes new legislation and you are trying to understand what it means for you.

A fully insured plan is a group health plan where the employer purchases coverage directly from an insurance company. These plans are state regulated.

In a self-funded plan, the employer takes on most or all of the costs and provides the benefits directly to the employees. Most self-funded plans are regulated by federal law. There are some exceptions, such as the state of Connecticut's employee plan.

Medicaid, Medicare, Tricare, and plans purchased through the marketplace are regulated by federal law.

Commercial/Medicare/Medicaid/ Tricare/Secondary Insurance

A little more than half of people living in the United States of America are on commercial health plans. Commercial plans are provided by private companies rather than by the government. Most commercial plans are offered by employers (employer-sponsored health plans).

Medicare is federal health insurance for people 65 or older and for some people under 65 who have been approved for federal disability.

Medicaid, also known as Medical Assistance (MA), is a joint federal and state program that helps cover medical costs for some people with low income. Since it is a joint program, the federal government has general rules that Medicaid programs must follow, but each state funds its own program. Eligibility requirements and benefits vary from state to state. Children with JIA qualify for Medicaid regardless of income or with higher income limits in some states. You can find out more about your state's Medicaid program and eligibility at www.medicaid.gov/about-us/beneficiary-resources/index.html#statemenu. Not all of the state Medicaid websites are clear about who qualifies. If you are unsure about eligibility requirements in your state, ask your hospital's social worker or call the number on the website.

TRICARE is the health plan for uniformed service members, retirees, and their families around the world.

Secondary insurance is the second health plan when you have more than one plan. For example, if you have a health plan from your employer, a health plan from the marketplace, or TRICARE and also have Medicaid, Medicaid acts as secondary insurance. It's also possible to have a health plan through your employer and another one through your spouse's employer. You would choose which plan is the primary plan and which serves as the secondary insurance. If you have more than one health plan, you need to notify each plan. The plans will work together to cover your claims. In most cases, secondary insurance increases your healthcare coverage.

TIP: Children diagnosed with JIA may qualify for Medicaid in some US states regardless of household income, with a higher household income limit, or based on the child's income. You can find out more about your state's Medicaid program and eligibility at www.medicaid.gov/about-us/beneficiary-resources/index.html#statemenu. Ask your hospital social worker if you are unsure if your child might be eligible for Medicaid in your state or for information on how to apply.

FSA vs HSA

Beth Flexible Spending Accounts (FSA) and Health Savings Accounts (HSA) allow you to put pre-tax money from your paycheck into an account to pay for eligible medical expenses. An FSA is created by the employer. An HSA can be created by either the employer or the employee. Money put into an FSA must be used each year. Money put into an HSA may be rolled over to the next year if unspent. An FSA can be used with any kind of health plan. An HSA may only be used with a high deductible health plan.

COBRA

The Consolidated Omnibus Budget Reconciliation Act (COBRA) outlines how employees and family members may continue health coverage after a job loss or after a loss in benefits. Additional information on COBRA, including frequently asked questions, can be found at www.dol.gov/general/topic/health-plans/cobra.

Changing Plans

If you are changing health plans, make sure your specialists and medicines are covered under the plan and be sure to provide the new plan information to your care team and pharmacy. If you are moving to a different plan by the same insurance company during a plan year, your deductible and out of pocket amounts may carry over to the new plan. If you are changing plan companies during a plan year, your deductible and out of pocket amounts will reset. If you are on a medicine that requires prior authorization, contact your care team as soon as possible so they can start the prior authorization process.

CLAIMS AND PRIOR AUTHORIZATIONS

Denied Claims

If you believe a test or treatment that was denied by your health plan should have been approved, call your health plan to find out why it was denied. Your health plan is required to provide the reason for the denial in writing. If it was denied because your care team accidentally used the wrong billing

or diagnosis code on the claim form, contact the billing department of your care team and ask them to revise and resubmit the claim.

If it was denied for a different reason and you want to appeal their decision, ask your insurance company how to appeal and what information is needed to appeal. The appeals process is different for each health plan. Depending on the reason the claim was denied, your care team may be able to help you with your appeal.

If your claim is still denied after an appeal, you can request a second-level appeal. For this appeal, your claim is typically reviewed by a medical director at your health plan. If it is still denied, you can request an Independent External Review. This is when an independent reviewer with the health plan and a doctor with the same specialty as your doctor reviews the appeal.

If after this, your claim is still not approved, you can try to talk to your employer's health benefits manager if you have one or use the resources at www.healthcare.gov/how-can-i-get-consumer-help-if-i-have-insurance.

If your claim is still not approved, you can try to contact your state representative's office and ask for help.

TIP: Do not just accept that a claim has been denied. First, contact your health plan to find out why and then contact your care team to correct any billing errors or find a solution to the problem.

Prior Authorization

Sometimes your doctor will need to get prior authorization (permission) or preauthorization from the health plan for certain medicines and procedures. Your rheumatology care team will submit the prior authorization request explaining why the medicine or procedure is "medically necessary." Your health plan will have requirements that need to be met before it will agree to the request. Each health plan has a different process for prior authorization that can range from a day to a few weeks. The health plan may approve or deny the prior authorization request.

If approved, you will be able to receive the medicine or procedure. Normally the medicine that requires prior authorization will need to be ordered through a specialty pharmacy. A specialty pharmacy provides medicine used to treat chronic or serious health conditions. If you are

prescribed a biologic, you will order it through a specialty pharmacy approved by your health plan. This will not be the same retail (or neighborhood) pharmacy that you normally use for your other prescriptions. If you are unsure of what specialty pharmacy to use, contact your health plan.

Please note that your health plan may approve the medicine for a limited period of time. Once this period is up, your care team will need to submit another prior authorization request. Be sure the request is submitted early enough so that your medicine is not delayed. If you are notified that you will need a new prior authorization, contact your care team so they can submit another prior authorization. Your care team may not be aware of the need for a new prior authorization if you do not tell them.

If your health plan denies the prior authorization, what happens next will depend on the reason the request was denied.

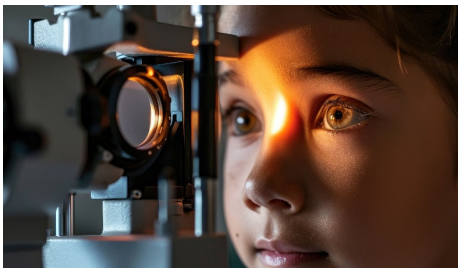
If a medicine was denied because the health plan requires "step therapy," this means you may need to try a lower cost medicine before the plan approves more expensive medicines. If you have already used the lower cost medicine without success or your care team believes that the lower cost medicine will not be effective, your care team can appeal the health plan's decision. Your care team will follow an appeals process that is different for each health plan.

If after appeal, the medicine is still denied, your care team can ask the health plan for a peer-to-peer review. This is when your rheumatologist discusses the need for the medicine with a doctor who works for the health plan. Your care team may also ask for an Independent External Review. This is when an independent reviewer with the health plan and a doctor with the same specialty as your doctor reviews the appeal. This whole process can sometimes take weeks or months.

If after this, your medicine is still not approved, you can try to talk to your employer's health benefits manager if you have one or use the resources at www.healthcare.gov/how-can-i-get-consumer-help-if-i-have-insurance.

TIP: Contact your care team right away if you receive a notice from your health plan letting you know you will need to submit another prior authorization. This will allow your care team to submit another prior authorization in time to prevent a delay in receiving a refill of your medicine.

INSURANCE COVERAGE



Eye Exams

It is important that patients diagnosed with juvenile idiopathic arthritis receive regular uveitis screening by an ophthalmologist. Since the screening is due to a medical condition, it will be covered by your health plan, not by vision insurance.

Traveling For Appointments

Since some states do not have any pediatric rheumatologists and many states only have one, you may have to travel to another state to get to your rheumatology appointments. Your plan may cover travel for the appointment, including lodging, if required. Contact your health plan to learn about your coverage.

If there is not an in-network pediatric rheumatologist on your plan, ask your health plan about coverage for out-of-network specialty care when no in-network specialist is available. There may be an authorization process you will need to follow before you see the pediatric rheumatologist in order for the health plan to cover the visit.

If there is an out-of-network pediatric rheumatologist hours closer than the closest in-network pediatric rheumatologist, contact your health plan to request to see the out-of-network specialist. If the health plan denies the request, you may appeal the decision.

Second Opinions

Most health insurance companies cover a second opinion. Contact your insurance company to ask about coverage.

Specialty Pharmacy

A specialty pharmacy provides medicine used to treat chronic or serious health conditions when the medicine is expensive, complex, or “high touch” (meaning it requires a lot of management and monitoring). If you are prescribed a biologic, you will order it through a specialty pharmacy approved by your health plan. This will not be the same retail pharmacy that you normally use for your other prescriptions. If you are unsure of what specialty pharmacy to use, contact your

health plan. Specialty pharmacies ship the medicine to you or you can request to have it shipped to a nearby retail pharmacy.

TIP: Contact the specialty pharmacy to refill your medicine a week before you need it (or longer if you think your care team will need to resubmit for prior authorization). Arrange for the medicine to be delivered Monday through Wednesday before the next dose is due. This will allow time for them to reship the medicine if it is lost in shipping.

Copay And Patient Assistance Programs

Drug companies often offer patient assistance programs (PAPs) for their more expensive medicines. PAPs provide financial assistance to help patients cover the cost of copays. Each company's program is different, but they all have a limit to how much assistance you can receive each year.

If you would like to learn if there are any assistance programs for your prescriptions, ask your care team or search online for the name of the medicine plus the words "patient assistance program." The website https://medicineassistancetool.org allows you to search by each medicine, but it is does not include all medicines with assistance programs. Some copay assistance programs offer immediate approval but others may require three or more days. Be sure to allow enough time for approval of the assistance before you order delivery of your medicine.

If you are on a biologic or other high-cost medication and your insurance requires you to use a generic version ("biosimilar"), you will need to contact the new drug company that makes the biosimilar to request copay assistance.

Some health plans include a feature that may be called a Copay Accumulator, Copay Maximizer or Accumulator Adjustment Program. If your health plan has this feature, payments from a drug company's discount program or PAP are applied to the plan deductible or out-of-pocket maximum.

Patients on government health plans, such as Medicaid, are not allowed to use PAPs. Medicaid has a low copay for appointments and medicines (no more than $8 at the time this toolkit was created). This makes the medicines much more affordable even without the copay assistance programs.

TIP: If you cannot afford your medicine, contact your care team. They may be able to offer you other resources or may be able to prescribe a different medicine.

ADDITIONAL RESOURCES

HealthCare.gov is a government website that educates Americans about the Affordable Care Act and includes helpful resources, including localhelp.healthcare.gov to talk to someone near you.

Arthritis.org is the Arthritis Foundation's website. Their Rx for Access (www.arthritis.org/rx-for-access) provides information on health coverage, and their helpline (800-283-7800) allows you to chat with licensed clinical social workers and trained staff.

FamiliesUSA.org is a national nonprofit dedicated to the achievement of high-quality, affordable health care and improved health for all.

Georgetown University's Center on Health Insurance Reforms (https://navigatorguide.georgetown.edu/) has developed an online resource for Navigators and others seeking information on the private insurance reforms of the ACA.

The Assistance Fund (www.tafcares.org) is an independent charitable patient assistance foundation that helps low income patients and families facing high medical out-of-pocket costs by providing financial assistance for their copayments, coinsurance, deductibles, and other health-related expenses through disease specific programs. Juvenile arthritis and uveitis are covered diseases.

The State Overviews (https://www.medicaid.gov/state-overviews/index.html) provide resources that highlight the key characteristics of states' Medicaid and CHIP programs.

If you travel far for appointments, you may be able to find a place to stay and get other support from Ronald McDonald House Charities (https://rmhc.org).

GoodRx is a healthcare company that tracks prescription drug prices in the US and provides drug coupons for discounts on medications (https://www.goodrx.com).

The Centers for Medicare & Medicaid Services has consumer rights, protections and resources and a Consumer Advocate Toolkit for the No Surprises Act (https://www.cms.gov/nosurprises).

AETNA provides information on the Transparency in Coverage Rule, Machine-readable file requirements, and the Consolidated Appropriations Act (https://www.aetna.com/individuals-families/member-rights-resources/rights/transparency-in-coverage.html)

INSURANCE TERMS

Accumulator Adjustment Programs: See Copay Accumulator

Appeal: A request for a plan to review a decision to deny coverage or prior authorization.

Biosimilar: A medicine that is a very similar but less expensive version of a biologic.

COBRA: The Consolidated Omnibus Budget Reconciliation Act gives you the right to temporarily continue employer health benefits for a fee after a job loss or reduction in work hours and benefits.

Coinsurance: Instead of a fixed amount of money, you pay a set percentage of appointment, medication, or test costs. Expensive biologics often have coinsurance instead of copays. Once your Out-of-Pocket Maximum has been reached for the year, you will no longer have any coinsurance until the start of the next plan year.

Consumer Assistance Program: State programs that assist you with health plan questions and problems. Find your state programs at www.cms.gov/CCIIO/Resources/Consumer-Assistance-Grants

Cost Sharing: Your share of the costs of your appointments, treatments, or tests. The plan Deductible and Out of Pocket amounts are examples of cost sharing.

Copay: A fixed amount of money that pay for your care, including an appointment, medication, or test. Once your Out-of-Pocket Maximum has been reached for the year, you will no longer have any copays until the start of the next plan year.

Copay Accumulator or **Copay Maximizer** or **Accumulator Adjustment Programs:** A feature in some health plans where payments from a drug manufacturer's discount or copay program does not get applied to the plan deductible or out-of-pocket maximum.

Deductible: The amount you pay toward your care before the health plan starts paying.

Drug Formulary or **Preferred Drug List (PDL)**: A list of drugs or medications your health plan covers. The list is divided into prescription tiers. Many medications require prior authorization, especially those medications in the higher tiers.

Exclusions: Treatments and services that are not covered by your health plan.

FSA: A **Flexible Spending Account** lets you put pre-tax money from your paycheck into an account to pay for eligible medical expenses. See the FSA vs HSA section to learn the difference between the two options.

High Deductible Health Plans: A plan with a higher deductible than a traditional insurance plan.

HSA: A **Health Savings Account** lets you put pre-tax money from your paycheck into an account to pay for eligible medical expenses. See the FSA vs HSA section to learn the difference between the two options.

Out of Network: Care providers or hospitals not under contract with your health plan provider. The services by out of network providers will cost more than those in network.

Out of Pocket Maximums: This is the most you will have to pay for your healthcare during the plan year. This does not include costs for care not covered by your health plan.

PCP: A **Primary Care Provider** is a pediatrician or family medicine provider.

Prescription Tiers: Health plans divide medications into different groups with least expensive medicines in the lower tiers and the more expensive medicines and specialty drugs, like biologics, in the higher tiers.

Prior Authorization: Sometimes you will be required to get prior authorization (permission) from the health plan for certain medicines and procedures. Your rheumatology care team will submit the prior authorization request to the health plan for approval.

Retail Pharmacy: A retail pharmacy is located in the community and fills prescriptions that treat common health conditions such as high blood pressure or infections.

Specialty Pharmacy: A specialty pharmacy provides expensive, complex, or high touch medicines used to treat chronic or serious health conditions.

Step Therapy: A practice used by health plans that requires patients to try lower cost medicines before approving more expensive medicines.

Contact Information

Toolkit Creators

This toolkit was created for use for juvenile idiopathic arthritis patients by members of PR-COIN. **Contact us at www.pr-coin.org/contact-families!** This toolkit was authored by Kerry Ferraro with contributions from members of PR-COIN Parent Working Group and Dr. Esi Morgan.

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PR-COIN Mission

The mission of PR-COIN is to build a thriving and inclusive community of patients, families, clinical teams and researchers that uses quality improvement science to deliver exceptional and equitable health care to children with rheumatic diseases and to bring research discovery to patients faster.