Insurance Coverage for Costly Rare-Disease Treatments

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Little Hercules Foundation

About Little Hercules Foundation

Little Hercules Foundation is a registered, non-profit 501(c)(3) organization based in Dublin, Ohio. Little Hercules Foundation got its start in January 2013 when three moms, two of whom had sons diagnosed with Duchenne Muscular Dystrophy, decided to host events to help fund research. Since then, Little Hercules Foundation has grown into much more.

For the past several years, the Little Hercules team has been providing direct support to patients and families who need assistance with their insurance appeals for approved treatments for Duchenne Muscular Dystrophy. In addition to the direct support they provide, the team advocates for the entire rare disease community on key issues such as drug approvals, legislative priorities surrounding timely treatment access, and engaging with the government programs that many rare disease patients rely on. The foundation is committed to working to ensure every rare disease patient gets access to the treatments and care they need and deserve. This commitment includes working with other patient advocacy organizations to provide support surrounding treatment access.

Agenda

- Health insurance overview
- Patient access issues
- How LHF addresses access concerns

Types of Health Coverage

- Employer-Sponsored
- Marketplace (a.k.a. Exchange)
- Medicaid
- CHIP (Children’s Health Insurance Program)
- Medicare

Employer-Sponsored Plans

- Employer provided healthcare for employees and their dependents
- Cost of premiums are shared between employer and employees
- Employer selects insurance(s) and options available
  - Company
  - Common plan types
    - PPO
    - HMO
    - EPO
  - Plans may be “fully insured” or “self-insured”
- Options can change periodically
- May be a waiting period before employees can enroll

Marketplace (Exchange)

- Private health plans that must be preapproved by each state insurance department before they are sold on the marketplace
- You select the company and the plan
- Four “metal” categories that show how costs are shared between you and health plan
- May be subsidized based on income
- Open enrollment annually (November 1-January 15)

  You can enroll outside of these dates **if you qualify for a special enrollment period

Medicaid

- Largest source of health coverage in the United States
- Jointly funded by the federal government and the states
- Serves low-income people of every age
- Patients pay little to no cost for covered medical expenses
- Coverage is provided through managed care, direct payment (fee-for-service) or a combination of the two

Children’s Health Insurance Program (CHIP)

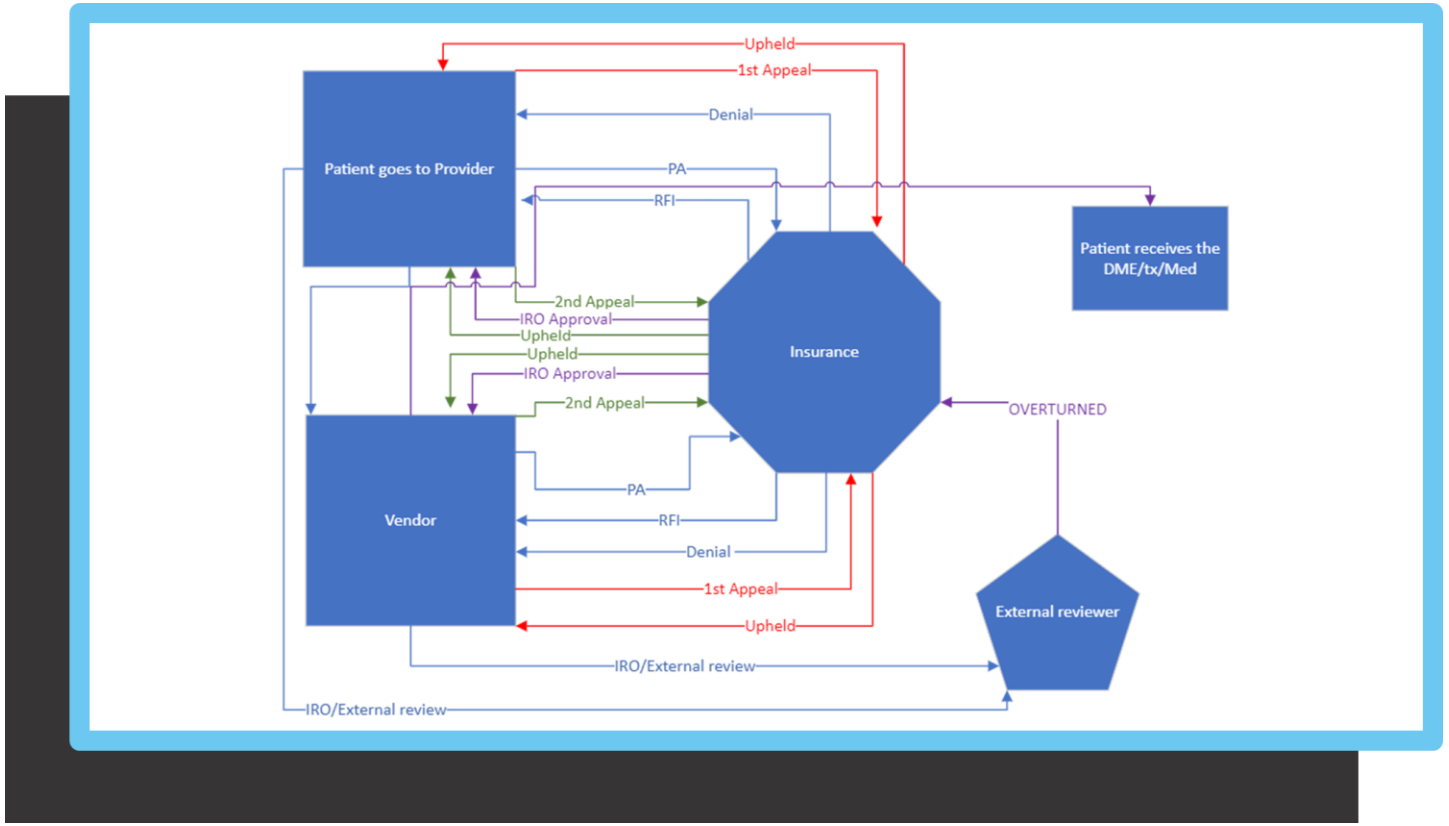
- Coverage for children whose families earn too much money for Medicaid
- Requirements differ from state to state
- Some states charge a monthly premium
- Application can be made at any time

Medicare

- Federal health insurance program
- Covers older adults, some people with disabilities and/or certain health conditions
- Choice of delivery systems
  - Traditional Medicare
  - Advantage Plan
- Premium assistance may be available
- Open enrollment October 15-December 7

What the Coverage Process Should Look Like

What the Coverage Process Actually Looks Like



Appeals & Grievances

Things You Can You Appeal

- Your request for a health care service, supply, or prescription drug is denied and you believe you should receive it
- Your request for payment for health care or a prescription drug you already received is denied
- Your request to change the amount you must pay for a prescription drug is denied
- You are getting coverage for an item and the plan stops paying

Common Reasons for Denial

- Services not medically necessary
- Services are experimental/investigational
- The effectiveness of the treatment has not been proven
- Not covered/excluded from benefit
- Lack of documentation

When to File a Grievance

- A staff member within the health plan treated you poorly or an adverse decision was a direct outcome due to the poor treatment of a staff member
- The health plan refused to make a determination on a service, and you can show that your health was harmed in some way. (this may be dismissed, however, it is worth a try)
- Anything that does not involve a decision that the plan makes on a service
- Your plan did not decide on your precert, claim, appeal within the required length of time (this is also something you can file a complaint with a regulating body about)

How to File an Appeal or Grievance

- For grievances, call the number on the back of your insurance card and state you would like to file a grievance. Do not hang up until you are allowed to do so. You can also go to your insurance website and the process should be available there.
- For appeals, your appeal rights and instructions will be included in the denial/uphold letters that you and your provider receive.

Other Options When External Review is Not Successful

- Outside funding from charitable organizations
- Media campaigns
- Government/elected officials
- Insurance commission
- Regulating organizations (if applicable)
- Court

Coverage Challenges for Rare Patients

- Copay accumulators
- Treatment carve outs/benefit design (specialty pharmacy)
- Condition carve outs
- Alternative funding programs

How LHF Assists Patients and Families

- Navigating insurance options and the insurance process
- Appeals
- Assistance with other options for pursuing coverage
- Policy/legislative fixes
- Direct engagement with payers
- Working alongside other organizations to address access barriers

Thank You!