

Genetics Funding Sources

October 2025

Genetic testing and care may have out-of-pocket costs. Below is a list of possible resources to assist with those expenses.

[VEN](#) Family Support Fund--Up to \$1500 for Medically Necessary Supplemental Funds.

Criteria includes:

- Have a chronic physical, medical, or developmental condition
- Requires health and related services of a type or amount beyond that required by children generally
- Children and families who earn at or less than 500% of the Federal Poverty Level

[National Organization for Rare Disorders](#) (NORD): For certain rare conditions; Patient Assistance Program includes free drug, co-pay and premium assistance, travel/lodging assistance for clinical trials, and expanded or emergency access.

- Must have an applicable diagnosis or physician referral.
- Must currently live in the United States.
- Must meet NORDs financial need criteria (by condition)
- Maximum award levels vary by program. Awards are made for a calendar year, and patients may reapply for subsequent years. NORD can offer same day approval for programs.

[Aubrey Rose Foundation](#) helps families with children who are currently living with a life-threatening medical condition. Grants are awarded quarterly based on need (until annual funds have been exhausted) and are considered for outstanding medical bills that insurance will not cover. [Bills](#) must be medically necessary.

[Chive Charities](#) spreads awareness by sharing stories for individuals with rare medical diagnoses, first responders, military families, and veterans, as well as providing grants to individuals and non-profit organizations. They can help provide therapy equipment like adaptive tricycles and robotic walkers to service dogs, wheelchair-accessible vans, and a wide range of medical, mobility, and therapy items.

- Chive Charities utilizes NORD and GARD databases and physical documentation to confirm the diagnosis and rarity of our rare medical applicants
- Applicants will be asked to provide a letter from a medical professional confirming diagnosis and the need for the requested grant item



HealthVermont.gov
802-863-7200



- Grant items must either improve quality of life or be medically related and not fully covered by insurance
- Applicants who've fundraised over \$30,000 may not be eligible for a grant and all applicants are required to report on fundraising activity in the application
- Applicants with income above \$100,000 may not be eligible for a grant
- Chive Charities does not cover past-due medical bills, rent, mortgage or car payments, funeral costs, lost family income, or experimental procedures without governmental body approval.

[Oracle Health Foundation](#) funds treatment, travel expenses, and vehicle modifications not covered by insurance, for families with children under 18 years of age.

- The child must be 18 years of age or younger (a person 19–21 may be considered if they are in a child-like mental state).
- The child must be under the care of a physician.
- The request must be clinically relevant to a specific healthcare need of the child.
- There must be no existing insurance coverage for the requested expenses.
- One request per 12 months, per child for a maximum of three times in a child's lifetime.

[Needy Meds](#) provides a database to help families find scholarships for prescriptions, camps, and other diagnosis-specific assistance.

- Each program has its own qualifying criteria

[The Weber Foundation](#) provides direct financial assistance to individuals and their families who are facing life-threatening illnesses or other catastrophic situations.

- Grants are limited to residents of the following states: Maine, Vermont, New Hampshire, Massachusetts, Connecticut, Rhode Island, New York and Pennsylvania.
- Applications must be supported by medical reports and/or financial statements
- Requests for medical assistance must establish a clear, unmet, financial need directly related to a diagnosed medical condition
- Applicants must provide a reasonable estimate for the cost and establish that it is not covered by medical insurance. Payments are made to the medical provider.
- Applicants must provide federal income tax returns for at least two prior years
- Unable to assist with accessible vehicles

[PAN Foundation](#) provides financial assistance to underinsured individuals with certain chronic/rare diseases. The program can help pay for out-of-pocket medication costs, co-pays, insurance premiums, and travel expenses. You can apply for a PAN grant if:

- You currently are in treatment or taking medication for your diagnosis, or
- You got treatment in the last 90 days, or
- You are scheduled to begin treatment in the next 120 days
- You are currently getting treatment for the disease named in the disease fund.
- Your prescribed medication is listed as a covered medication for your disease fund.
- You have health insurance that covers your qualifying medication or product. Note: Health insurance requirements vary by fund.
- Your income falls at or below the federal poverty level specified by the disease fund.

[Healthwell Foundation](#) provides financial assistance from one of their disease-specific funds for eligible people to help pay for coinsurance, copays, premiums, and deductibles for certain medications and therapies.

- Must be receiving treatment for a [covered disease](#)
- Must have insurance that covers your medication
- Receiving treatment in the US
- Income within 400-500% of the Federal Poverty Level

[United Healthcare Children's Foundation](#)

- Primary health insurance must be through a commercial health plan (through an employer or individually purchased). Secondary insurance through Medicaid or CHIP is allowed.
- Child must be 16 years old or younger at time of application
- Must meet income requirements listed under eligibility on website

Many of these resources were pulled from the [Grant Funding Resource List](#).

If you're looking for financial assistance around a specific condition, reach out to a [Care Consultant](#) or [Genetics Navigator](#).