

Spinal muscular atrophy

Understanding financial pathways: support and resources for SMA treatment in the US

Essential resources and strategies for securing support and staying ahead financially

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Introduction

Spinal muscular atrophy (SMA) is a genetic disease affecting the nervous system, leading to muscle weakness and atrophy. SMA can affect individuals of all ages, and while there is no cure, treatments are available to manage symptoms and enhance the quality of life. However, these treatments can be expensive. Fortunately, numerous financial resources are available to help patients access the care they need.

Organizations and foundations offering financial assistance

Several organizations and foundations offer financial assistance for SMA treatment. These organizations may provide grants, scholarships, or other types of financial aid to help patients cover treatment costs, travel, and other expenses.

Here are a few organizations that offer financial assistance for SMA treatment:

- The PAN Foundation: The PAN Foundation offers a patient assistance program for people living with SMA. Patients who qualify can receive \$2,000 per year in financial assistance to pay for deductibles, copays, and coinsurance costs associated with their treatment [1].
- Co-Pay Relief: Co-Pay Relief offers a Spinal Muscular Atrophy Health Equity Fund that provides financial assistance to eligible patients [2].
- Cure SMA: Cure SMA offers a variety of support programs for individuals and families affected by SMA, including scholarships to attend the Annual SMA Conference [3].
- Families of Spinal Muscular Atrophy (FSMA): FSMA is a national organization that offers a wide variety of information, services, and support to families caring for someone with SMA [4].

- The Spinal Muscular Atrophy Foundation: This foundation is dedicated to accelerating the development of a treatment for SMA, the number one genetic cause of death in infants and toddlers [5].
- The Muscular Dystrophy Association (MDA): The MDA funds research and provides support services for families affected by muscular dystrophy and other neuromuscular diseases, including SMA [6].

Support and care packages

In addition to financial aid, some organizations offer support and care packages to help ease the burden of living with SMA. These packages may include essential items that can improve daily living and reduce some expenses.

- **Cure SMA:** Cure SMA offers teens and adults in the SMA community support and independence assistance packages filled with helpful items recommended by other adults with SMA. These items allow for increased independence with certain tasks. This program is offered to any teen or adult with SMA in the U.S [3].

Support and care packages

Grants and scholarships are a valuable form of financial assistance that does not need to be repaid. Several organizations offer these programs specifically for SMA patients.

- Cure SMA: Cure SMA offers scholarships for individuals and families to attend the Annual SMA Conference. The Adults with SMA Scholarship program offers a scholarship to every adult with SMA and their personal care assistant. The scholarship covers registration fees, a travel stipend, and one hotel room for three nights at the specified conference hotel. The First Time Attendee Scholarship program is a scholarship that covers any individual with SMA who has never attended the Annual SMA Conference and up to four immediate family members [3].

Co-pay assistance programs

Co-pay assistance programs help patients cover the out-of-pocket costs associated with their medications. These programs are often offered by pharmaceutical companies.

- Biogen: Biogen offers the SMA360^o™ program to help patients with insurance and financial assistance counseling. This program helps patients understand their insurance benefits for SPINRAZA and identify the most affordable way to start and stay on treatment [7].
- Genentech: Genentech offers the Evrysdi Co-pay Program, where eligible patients with commercial insurance could pay as little as \$0 per 30-day supply of Evrysdi. The program covers the rest of your co-pay or co-insurance, up to \$25,000 in assistance per calendar year [8].

Government assistance programs

There are also government programs that provide financial support for SMA treatment. These programs may include Medicaid, Medicare, and Social Security Disability Insurance (SSDI) [9].

- **Medicaid:** Medicaid is a joint federal and state program that helps with medical costs for some people with limited income and resources. Medicaid programs vary from state to state, but most health care costs are covered if you qualify for Medicaid [9].
- **Medicare:** Medicare is a federal government program that provides health insurance for people age 65 or older and younger people with disabilities. Medicare offers different plans with different coverage options.
- **Social Security Disability Insurance (SSDI):** SSDI is a federal program that provides financial assistance to people who cannot work due to a disability. To qualify for SSDI, you must have worked in jobs covered by Social Security and have a medical condition that meets Social Security's definition of disability.

In addition to these programs, the MDA funds research and provides support services for families affected by muscular dystrophy and other neuromuscular diseases, including SMA [10]. Cure SMA also plays a role in attracting industry and government funding for clinical trials [11].

Pharmaceutical company programs

Many pharmaceutical companies offer various programs to support SMA patients beyond co-pay assistance. These programs may include patient support services, access programs, and resources for navigating insurance and financial assistance.

- **Novartis Gene Therapies:** Novartis Gene Therapies has a program called OneGene that helps families navigate insurance and financial assistance. They even have a dedicated case coordinator who will work with your doctor and a family ambassador to support you throughout the process. OneGene assists with benefits investigation and verification processes, helps with buy-and-bill and ZOLGENSMA reimbursement, provides support on financial assistance programs for eligible patients, tracks ZOLGENSMA from prescription to delivery at your institution, and connects you to SMA diagnostic anti-adenovirus 9 (AAV9) antibody testing and reimbursement through the Novartis Laboratory Testing Program [12].
- **AbbVie:** AbbVie offers patient assistance programs that provide free AbbVie medicines to qualifying patients [14].

- Past programmes: Novartis created the Zolgensma® (onasemnogene abeparvovec) global Managed Access Program (gMAP) in 2020 to broaden global access to Zolgensma. The program was available and provided the gene therapy free of charge to eligible patients in countries where it was possible to make Zolgensma available, where it had not yet received approval, or where no access pathway existed. While the program closed to new patient requests at the end of July 2024, with the last allocated patient treated by December 2024, it highlights the efforts made by pharmaceutical companies to improve access to treatment [13].

Accessing treatment

Navigating insurance coverage and finding ways to afford SMA treatment can be challenging.

Here are some resources and strategies that can help:

Navigating insurance coverage

Understanding your insurance benefits and coverage for SMA treatment is crucial. Here are a few resources that can help:

- **Cure SMA:** Cure SMA offers insurance resources to help families understand their insurance benefits and navigate the appeals process [15].
- **Together in SMA:** Together in SMA provides an insurance guide for individuals with SMA and their caregivers [16].

MySMAteam: MySMAteam offers resources on obstacles and tips for sticking with SMA therapies [18].

Fundraising and crowdfunding

If you are having trouble affording SMA treatment, you may want to consider fundraising or crowdfunding. Here are a few resources that offer tips on fundraising and crowdfunding for SMA treatment:

- WhyDonate: WhyDonate provides a platform for crowdfunding for SMA treatment [19].
- Cure SMA: Cure SMA offers resources and tips on fundraising for SMA treatment [20].
- GoFundMe: GoFundMe is a popular crowdfunding platform that can be used to raise money for SMA treatment [22].
- SMA UK: SMA UK offers fundraising tips and resources [25].
- SMA News Today: SMA News Today provides information on crowdfunding for SMA treatment [26].

While crowdfunding can be a powerful tool for raising funds, it's important to be aware of the potential ethical issues and power imbalances associated with it. Patients who rely on crowdfunding are in a vulnerable position and may face challenges in negotiating with pharmaceutical companies, the government, and fundraising platforms [27].

Emotional support and guidance

SMA can be a challenging disease for patients and families to cope with. Here are a few resources that provide emotional support and guidance:

- MySMAteam: MySMAteam offers resources on parenting a child with SMA [28].
- SMA News Today: SMA News Today provides information on psychological support for SMA patients and families [29].
- Cure SMA: Cure SMA offers resources on caring for emotional and mental health [30].
- HealthCentral: HealthCentral provides information on how to get off the emotional rollercoaster with SMA [31].

Conclusion

SMA is a severe disease, but treatments are available to help manage symptoms and improve the quality of life. While these treatments can be expensive, many financial resources are available to help patients access them. If you are struggling to afford SMA treatment, explore the resources listed in this report. Remember, you are not alone on this journey. With the right information and support, you can overcome the financial challenges of SMA treatment and focus on what matters most: your health and well-being. It's also important to remember that a comprehensive care plan should address both medical and non-medical needs, including medical treatment, financial assistance, emotional support, and social services [33].

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