

Primary biliary cholangitis

Exploring financial assistance options for primary biliary cholangitis treatment in the US

Essential resources and strategies for accessing financial support and reducing treatment costs

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Introduction

Primary biliary cholangitis (PBC) is a chronic liver disease that can be challenging to manage, both physically and financially. The good news is that there are resources available to help you access the care you need, including assistance with medication costs, insurance premiums, and other medical expenses. This article will guide you through various financial assistance options, including programs offered by pharmaceutical companies, government agencies, non-profit organizations, and hospitals.

The information presented in this article was gathered through a comprehensive research process, including online searches, consultation of relevant websites (such as those of government agencies, patient advocacy organizations, and pharmaceutical companies), and review of patient resources and support materials.

Patient advocacy organizations

Navigating the healthcare system can be confusing [1], but you don't have to do it alone. Several organizations provide support and resources for PBC patients.

Here are a few key organizations:

PBCers Organization:

- This group offers online and in-person support for PBC patients, caregivers, and healthcare professionals.
- They provide peer support, educational resources, and the latest information on PBC.
- You can connect with other patients, find knowledgeable healthcare providers, and support ongoing research [2].
- They host an annual conference that provides an opportunity for PBC patients, caregivers, and healthcare professionals to connect, learn from experts, and share experiences [2].
- The PBCers Organization also maintains a Patient Registry, which allows PBC patients to share information about their condition with researchers and learn about clinical trials [2].

American Liver Foundation:

- This national organization offers a wealth of information on liver diseases, including PBC.
- They provide support groups, educational resources, and advocacy for patients and families [5].
- They also have a patient forum, ALF Inspire, which provides a platform for patients and caregivers to connect, share experiences, and ask questions [7].

The Community Liver Alliance:

- This organization supports the liver community through awareness campaigns, prevention programs, education, advocacy, and research.
- They offer online support groups and a national support helpline to connect you with resources and clinical trials in your area [5].

Canadian PBC Society:

- While based in Canada, this organization offers resources and support that may be helpful to PBC patients in the US.
- They have regional groups that provide support and encouragement, education, and information, and they also fundraise for research on PBC [7]. You can find more information on their website: pbc-society.ca.

Pharmaceutical company assistance programs

Many pharmaceutical companies that manufacture PBC treatments offer financial assistance programs to help patients access their medications [12].

Here are a few examples:

Intercept Pharmaceuticals:

- Intercept offers the Interconnect® patient support program, which provides disease education, treatment guidance, and financial assistance options [7].

Gilead:

- Gilead's Support Path® program offers co-pay coupon programs for commercially insured patients and a patient assistance program for those who lack insurance coverage or are underinsured [12]. They also have an interim support program for patients with insurance delays or interruptions in coverage.

To find out if the pharmaceutical company that manufactures your medication offers a financial assistance program, visit their website or contact their customer service department [14].

Government programs

Several government programs offer financial assistance for medical treatment, which may help cover the costs of PBC care.

These include:

Medicare

A federal health insurance program for people over 65 and some younger people with disabilities [1].

Medicare has different parts that cover various aspects of medical care:

- Part A covers inpatient hospital stays, care in a skilled nursing facility, hospice care, and some home health care.
- Part B covers certain doctors' services, outpatient care, medical supplies, and preventive services.
- Part C (also known as Medicare Advantage) offers an alternative way to get your Medicare benefits through private insurance companies.
- Part D helps cover the cost of prescription drugs.

Medicaid

A joint federal and state program that provides health coverage to low-income individuals and families [1].

- Medicaid waivers are state-run programs that use federal and state funds to pay for health care for people with certain health conditions [16].
- In some states, families can apply for a Medicaid waiver that waives the family income requirement and looks only at the disabled person's income.

Children's Health Insurance Program (CHIP)

- Provides low-cost health coverage to children in families who earn too much money to qualify for Medicaid but cannot afford private insurance [1].

You can explore these programs and their eligibility requirements on the official government benefits website (<https://benefits.gov>) [16] or by contacting your state's Health Department. State social services agencies can also provide direct assistance to people with limited access to health care and can offer referrals to local resources [14]. The National Institutes of Health (NIH) also provides financial support in the form of grants for various research-related activities [17]. You can contact 211, a 24/7 service that connects people with local assistance, including health care and insurance assistance [18].

Rare disease assistance programs

The National Organization for Rare Disorders (NORD) offers a rare disease assistance program called RareCare® [19]. NORD is a leading independent non-profit organization dedicated to supporting individuals and families affected by rare diseases. RareCare® provides various forms of financial assistance to help patients with rare diseases access necessary care and treatment.

Medication Assistance

- Helps cover the cost of prescription medications.
- Eligibility: Varies depending on the specific medication and program.

Insurance Premium Assistance

- Helps pay for health insurance premiums.
- Eligibility: Varies depending on the specific program and the patient's income and resources.

Co-pay Assistance

- Helps cover the cost of co-pays for medical services.
- Eligibility: Varies depending on the specific program and the patient's insurance plan.

Diagnostic Testing Assistance

- Helps cover the cost of diagnostic testing for rare diseases.
- Eligibility: Varies depending on the specific program and the type of testing needed.

Travel Assistance

- Helps cover the cost of travel for clinical trials or consultations with specialists.
- Eligibility: Varies depending on the specific program and the distance traveled.

For any of the above, contact NORD or visit their website <https://rarediseases.org/contact/> for more information.

Hospital financial assistance programs

Many hospitals offer financial assistance programs, sometimes called "charity care," to help patients manage their medical expenses [20]. Nonprofit hospitals are required by law to offer these programs, and many for-profit hospitals also have similar programs. These programs may reduce or eliminate medical bills for patients who qualify.

Some states have charity care laws that require hospitals to provide free or discounted care to patients meeting certain requirements, often based on income [21]. Some of the states that offer these protections include California, Connecticut, Illinois, Maine, Maryland, Nevada, New Jersey, New York, Rhode Island, and Washington.

The Affordable Care Act (ACA) requires hospitals to have a written Financial Assistance Policy (FAP) and a written Emergency Medical Care policy [21]. These policies outline the hospital's financial assistance programs and eligibility requirements.

To find out about financial assistance programs offered by a specific hospital, contact the billing department of the hospital or medical facility where you receive treatment.

Tips for saving on medications

In addition to financial assistance programs, there are other ways to save money on your PBC medications:

Ask for generic versions

- Whenever possible, ask your doctor if there is a generic version of your medication available [18]. Generic drugs are just as effective as brand-name drugs but often significantly cheaper.

Contact pharmaceutical companies

- Contact the pharmaceutical companies that manufacture your medications to inquire about potential cost-saving options [14]. Some companies may offer patient assistance programs, discounts, or free samples to eligible patients.

Additional support for insured individuals

If you already receive coverage from Medicaid, Medicare, ACA Marketplace, or other insurance, additional programs may provide further support [14]:

Medicare Savings Programs

- There are four Medicare Savings Programs that may be able to help with Part A and Part B premiums, deductibles, coinsurance, and copayments.

Medicare Extra Help

- This program can help you pay Medicare Part D costs that cover prescription drugs.

Independent foundations and charities

In addition to government programs, numerous independent foundations and charities offer financial assistance for medical treatment, including PBC.

Here are a few notable organizations:

The Assistance Fund

- This independent charitable patient assistance organization helps patients with high medical out-of-pocket costs [22].
- They offer financial support for copays, health insurance premiums, and incidental medical expenses related to FDA-approved prescription medications.

Patient Access Network (PAN) Foundation

- PAN provides financial assistance to underinsured patients with life-threatening, chronic, and rare diseases [1].
- They help cover out-of-pocket costs for prescription medications, including those for PBC.
- They also offer a web-based app called FundFinder, designed to quickly notify registered users when financial assistance for their condition becomes available from any of the charitable patient assistance foundations [15].

HealthWell Foundation

- This non-profit organization helps underinsured patients access care by assisting with copays, premiums, deductibles, and out-of-pocket expenses [1].

Leukemia & Lymphoma Society (LLS)

- While primarily focused on blood cancers, the LLS offers resources that may be helpful to PBC patients facing financial challenges [28].
- Their Patient Aid Program provides a one-time \$100 stipend to eligible blood cancer patients to help offset non-medical expenses.
- They also have a Medical Debt Case Management Program that may be helpful to PBC patients struggling with medical debt.

Patient Advocate Foundation

- This organization has an independent division that provides small grants to patients who meet financial and medical criteria [29]. Grants are provided on a first-come, first-served basis until funds are depleted.

These are just a few examples, and many other foundations may offer assistance for PBC patients. Other organizations that may be able to help include Accessia Health, CancerCare, and Good Days [25]. You can use online resources like the PAN Foundation's website to find a comprehensive list of patient assistance organizations [25].

Online resources for medical billing and insurance

Navigating medical billing and insurance can be complex. It's important to understand your insurance policy and what it covers in advance of any illness or injury [30].

Fortunately, several online resources can help you understand your coverage and manage your medical expenses:

Understanding Your Policy

- Your insurance company's website: Most insurance companies have online portals where you can access your policy information, claims status, and find answers to frequently asked questions [31].
- Healthcare.gov: This website provides information about health insurance options, including government programs and the Health Insurance Marketplace [36].

Finding Providers and Managing Bills

- Online provider directories: These directories can help you find healthcare providers within your insurance network [32].
- Centers for Medicare & Medicaid Services (CMS): The CMS website offers resources and guides on understanding your medical bills, applying for financial assistance, and appealing health plan decisions [34].

- **Medical billing clearinghouse:** A medical billing clearinghouse, like Claim.MD, allows you to electronically submit claims to insurance companies [36]. They can also help verify client eligibility, check claims for errors, and speed up efficiency.
- **Insurance billing solutions:** Software solutions can help you check your eligibility for services, determine if pre-approval is needed from the insurer, and manage your medical bills [36].

Common Health Insurance Terms

Here's a brief glossary of common health insurance terms:

- **Premium:** The amount you pay for your health insurance every month.
- **Deductible:** The amount you pay for covered health care services before your insurance plan starts to pay.
- **Copay:** A fixed amount you pay for a covered health care service, usually when you get the service.
- **Coinsurance:** Your share of the costs of a covered health care service, calculated as a percentage (for example, 20%).
- **Out-of-pocket maximum:** The most you pay during a policy period (usually a year) before your health insurance plan begins to pay 100% of the allowed amount for covered health care services.

Support groups for PBC patients

Connecting with other PBC patients can provide emotional support and valuable information about financial assistance. Support groups can provide a sense of community, reduce feelings of isolation, and offer valuable peer support. Here are some support groups where you can share experiences and advice:

- **PBCers Organization:** This organization offers online and in-person support groups for PBC patients [2]. In these groups, members discuss medical information, pain management, medications, research, transplantation, and the emotional challenges of living with PBC [4]. You can contact the PBCers Organization at pbcers@pbcers.org or visit their website at <https://PBCers.org>.
- **Community Liver Alliance:** They offer online support groups specifically for PBC patients [37]. Their PBC Patient Support Group is an online gathering of patients who discuss how to manage their symptoms, lifestyles, and support one another. A healthcare provider moderates the group and can offer guidance.
- **American Liver Foundation:** They have a Facebook group dedicated to people living with PBC called "Life with PBC" [7]. They also have a general patient forum, ALF Inspire [7].

PBC Foundation: This global patient organization provides online support to people with PBC and their families and friends [7]. You can contact the PBC Foundation at info@pbcfoundation.org.uk or visit their website at <https://pbcfoundation.org.uk>.

Tips for seeking financial assistance

- Be proactive: Don't wait until you're in a financial crisis to start seeking assistance. Start exploring your options as soon as you are diagnosed with PBC.
- Be persistent: Navigating the healthcare system can be challenging, but don't give up. If you are denied assistance from one program, try another.
- Keep organized records: Keep track of all your medical expenses, insurance information, and applications for financial assistance.
- Ask for help: Don't be afraid to ask for help from your doctor, a social worker, or a patient advocate. They can help you navigate the system and find the resources you need.
- Connect with other patients: Talk to other PBC patients about their experiences with seeking financial assistance. They may have valuable insights and advice to share.

Conclusion

Managing the financial burden of PBC treatment can be overwhelming, but remember that you are not alone. Many resources are available to help you access the care you need, including financial assistance programs offered by pharmaceutical companies, government agencies, non-profit organizations, and hospitals. By exploring the options outlined in this article and connecting with patient advocacy organizations and support groups, you can find the financial assistance you need to access quality care and improve your quality of life.

Remember to be proactive and persistent in seeking financial assistance. Navigating the healthcare system can be challenging, but it's important to advocate for yourself and explore all available options. Contact multiple organizations and programs to find the best fit for your needs.

Connecting with other PBC patients through support groups can provide emotional support, reduce feelings of isolation, and offer valuable peer support. Don't hesitate to reach out to others who understand what you're going through.

Living with PBC can present various challenges, but with the right support and resources, you can manage your condition and live a full and meaningful life.

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