COMMUNITY LIVER ALLIANCE ™

GLOBAL AWARENESS. LOCAL IMPACT.

PRIMARY BILIARY CHOLANGITIS (PBC)

PATIENT AND CAREGIVER TOOLKIT

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Welcome

The purpose of the CLA's Primary Biliary Cholangitis (PBC) Toolkit is to empower patients, caregivers, and healthcare professionals by providing comprehensive, accessible, and up-to-date information on PBC.

This guide aims to educate readers about the disease, treatment options, and possible side effects, while also offering practical advice on navigating the healthcare system, managing the emotional and financial impacts of a diagnosis, and enhancing quality of life through supportive resources and self-care strategies.

Our goal is to assist individuals affected by PBC in making informed decisions about their care and to support them in their journey toward recovery and well-being.

How to Use This Toolkit

This toolkit is available for download to provide you with instant access to valuable information. Additionally, hard copies are available upon request. Feel free to share this resource with family, friends, and healthcare providers to ensure everyone involved in your care is informed and supported.

We hope this toolkit serves as a helpful guide throughout your PBC journey. Remember, you are not alone, and there are many resources and support systems available to help you manage and overcome the challenges you may face. For further assistance, do not hesitate to reach out to our team or visit our website for additional information and support.

PBC Toolkit

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Understanding PBC

What is PBC?
Primary Biliary Cholangitis (PBC) is a chronic liver disease that happens when the body's immune system mistakenly attacks the small bile ducts inside the liver.

Those bile ducts normally carry bile, a fluid that helps your body digest fats and get rid of toxins. When the ducts become damaged, bile builds up in the liver, which can cause inflammation and scarring over time (a condition called fibrosis).

If the disease isn't managed, that scarring can progress and affect how well the liver works — but the good news is that early detection and treatment can help slow or even stop damage.

Who Gets PBC?

- It most often affects women, typically between the ages of 30 and 60.
- PBC is not caused by alcohol or diet, but by an autoimmune response — meaning the body is attacking its own healthy cells by mistake.

What We Know About Risk Factors

- PBC seems to develop because of a mix of genetics, environment, and immune system triggers — not because of anything a person did or didn't do.
- Here are some factors that may play a role:
  - Genetics: It can run in families. Having a close relative with PBC or another autoimmune disease may increase risk.
  - Gender: About 9 out of 10 people with PBC are women, especially between the ages of 30 and 60.
  - Other Autoimmune Conditions: People with thyroid disease, rheumatoid arthritis, or celiac disease are more likely to develop PBC.
  - Environmental Triggers: Things like certain infections, chemicals, or toxins in the environment might activate the immune system in people who are genetically more likely to get PBC — but there's no single proven cause.

It's important to note:

- PBC is not caused by alcohol or drug use.
- It is not contagious — you can't catch it or spread it.
- It isn't caused by diet, though good nutrition helps manage it.

Signs & Symptoms of PBC

Some people don't notice symptoms at first, but over time, they might experience:

- Fatigue: Persistent tiredness that interferes with daily activities.
- Itching: Often severe, especially in the hands and feet.
- Jaundice: Yellowing of the skin and eyes.
- Dry Eyes and Mouth: Also known as sicca syndrome.
- Abdominal Pain: Especially in the upper right side.

Diagnosing PBC

How Is PBC Diagnosed?

PBC is often found through routine blood work long before serious symptoms appear. Diagnosis is confirmed with a combination of blood tests (especially AMA), imaging, and sometimes a biopsy.

The goal is early detection, so treatment can begin before significant liver damage occurs. Diagnosing Primary Biliary Cholangitis (PBC) usually begins when a doctor notices abnormal liver test results or when a patient has symptoms such as fatigue or itching. Because PBC develops slowly and symptoms can be mild at first, blood tests are key to finding it early.

Step 1: Blood Tests

The first and most important clue often comes from liver function tests (LFTs). These measure enzymes that show how well your liver is working.

- People with PBC often have elevated alkaline phosphatase (ALP) — an enzyme that rises when bile ducts are inflamed or blocked.
- A special antibody blood test called AMA (anti-mitochondrial antibody) is another hallmark of PBC. About 95% of people with PBC test positive for AMA, which helps confirm the diagnosis.
- Doctors may also look for other markers of liver or autoimmune activity.

Step 2: Imaging Tests
To make sure the liver problem isn't caused by something else (like gallstones or bile duct blockage), your doctor may order an ultrasound or MRI scan. These images help rule out other conditions and show how your liver and bile ducts look.

Step 3: Liver Biopsy (Sometimes)
In some cases, if blood and imaging results aren't completely clear, the doctor might recommend a liver biopsy — taking a small sample of liver tissue with a needle. This helps confirm how much inflammation or scarring is present and the stage of the disease.

Step 4: Ongoing Monitoring
Once diagnosed, people with PBC usually have regular checkups and blood tests to monitor liver health and how well treatments are working. Early diagnosis makes a big difference — with today's therapies, many people live long, healthy lives with PBC.

Treating PBC

Medications play a key role in helping manage Primary Biliary Cholangitis (PBC). The goal of treatment is to protect the liver, slow disease progression, and manage symptoms so you can live a full, active life.

This is a list of drugs used to treat PBC and their side effects.

Ursodeoxycholic Acid (UDCA)

- Brand names: Reltone, Actigall, Urso, Urso DS, Urso Forte
- UDCA (also called ursodiol) is the first-line treatment for PBC.
- It works by improving bile flow, reducing inflammation, and helping to prevent further liver damage.
- For many people, UDCA can slow or even stop the disease from worsening when taken regularly as prescribed.

Livdelzi (seladelpar)

- An oral prescription medicine that may be used to treat primary biliary cholangitis (PBC) in adults.
- Taken in combination with ursodeoxycholic acid (UDCA) in adults who have not responded well to UDCA
- Used alone in patients unable to tolerate UDCA.

Elafibranor (Iqirvo)

- An FDA-approved oral medication for treating primary biliary cholangitis (PBC).
- Elafibranor therapy helps reduce elevated alkaline phosphatase (ALP) levels and may normalize liver enzymes in PBC patients.
- Can be prescribed as combination therapy with ursodeoxycholic acid (UDCA) for patients with an inadequate UDCA response.
- As monotherapy for those with UDCA intolerance.

Symptom Management

- Some people with PBC may experience itching (pruritus), fatigue, or other symptoms.
- Your healthcare provider may recommend additional medications to help manage these, such as:
  - Treatments to relieve itching, like bile acid binders or antihistamines.
  - Vitamin supplements if your liver isn't absorbing nutrients properly.
  - Medications to help with fatigue or dry eyes and mouth, if needed.

Treating PBC

Medication Guidelines

1. Dosage and Timing
- Take your medication exactly as prescribed, at the same time each day.
- Some medicines work best with food ask your healthcare provider or pharmacist for specific instructions.
- Consistency is key: regular dosing helps protect your liver most effectively.

2. Side Effects
- Most people tolerate UDCA well, but some may experience mild side effects such as stomach discomfort or diarrhea.
- If you notice any new or bothersome symptoms, contact your healthcare provider they can adjust your dosage or recommend alternatives.
- If your liver doesn't respond fully to UDCA, your provider may discuss adding a second medication or other emerging therapies.

3. Missed Dose
- If you forget a dose, do not double up at your next scheduled time.
- Instead, contact your healthcare provider or pharmacist for advice on what to do next.
- Setting a daily reminder or using a pill organizer can help you stay on track.

Key Takeaway
Taking your medications consistently and staying in close contact with your healthcare team gives you the best chance of protecting your liver and feeling your best with PBC.

PBC Medication Tracker

Use this tracker to record your daily medications, dosages, and any side effects. Keeping a record helps you stay on schedule and provides helpful information for your healthcare team.

Date	Medication	Dose	Time Taken	Missed Dose?	Notes / Side Effects

Tips for Using This Tracker

- Review your tracker before medical appointments.
- Take a photo or bring it with you to share with your provider.
- If you miss a dose, note the reason and share it with your care team.
- Keep extra copies or use a digital app if you prefer mobile tracking.

Living with PBC

You don't have to face PBC alone. Whether it's reading stories from others, joining a support group, or speaking with a counselor, reaching out for connection and guidance can make a big difference in your emotional and physical wellbeing.

Dealing with Diagnosis

Being diagnosed with a chronic condition like PBC can feel overwhelming. These resources offer guidance on managing emotions, building resilience, and maintaining a positive outlook.

Recommended Reading & Online Materials:

- Book: "How to Be Sick: A Buddhist-Inspired Guide for the Chronically Ill and Their Caregivers" by Toni Bernhard – a compassionate, practical guide to coping with chronic illness.
- Book: "The Chronic Illness Workbook" by Patricia Fennell – focuses on coping strategies and stages of adjustment.
- Mayo Clinic – practical advice on managing daily life after diagnosis.
- PBCers - online and in-person support group for people with PBC, care partners and health care team members.
- National Institute of Diabetes and Digestive and Kidney Diseases: NIDDK research creates knowledge about and treatments for diseases that are among the most chronic, costly, and consequential for patients, their families, and the Nation.
- Global Liver Institute – Uniting Voices for a World Without Liver Disease.
- Community Liver Alliance - dedicated to supporting the community through liver disease awareness, prevention, education, advocacy and research.

Support Groups
Connecting with others who understand what you're going through can make a difference.
Local Groups:

- Ask your hepatologist, liver clinic, or hospital social worker about local liver disease or autoimmune condition support groups.
- Many Community Liver Alliance partner hospitals and regional liver foundations host monthly patient meetups or wellness programs.

Online Communities:

- PBC Foundation: – international community with webinars, peer support, and educational tools.
- Smart Patients – PBC Community: – moderated online discussion boards for patients and caregivers.
- Facebook Groups: Search "Primary Biliary Cholangitis Support" or "PBC Warriors" for active peer-to-peer groups (encourage joining verified, moderated spaces).

Counseling Services
Professional counseling can help you cope with the emotional and lifestyle changes that come with chronic illness.
Finding Therapists:

- Psychology Today Therapist Directory: – filter by specialty ("chronic illness," "medical issues," "health anxiety," or "chronic pain").
- American Psychological Association (APA): – find licensed psychologists who specialize in health psychology.
- Chronic Illness Peer Support (CIPS): – virtual peer-led emotional support sessions.
- More than PBC
- Rare Disease Advisor

Diet and Exercise Resources

The primary dietary advance for PBC patients is a healthy, well-balanced, whole-foods-focused and anti-inflammatory diet, most often a Mediterranean-leaning diet.

PBC dietary advice also includes avoiding alcohol, processed foods/sugars, and saturated fats. Sometimes, emphasis is placed on fat-soluble rich foods or fat-soluble vitamin supplementation, in addition to calcium supplementation, due to the risk of malabsorption and osteopenia/osteoporosis associated with the disease state.

The following reputable organizations have provided guidance on the PBC diet that patients should consider.

- Mayo Clinic
- Cleveland Clinic
- National Institute of Diabetes and Digestive and Kidney Diseases
- Community Liver Alliance

Regular physical activity can be an important part of living well with PBC.

Exercise helps improve energy, muscle strength, mood, and overall quality of life — and it supports your liver health by promoting circulation, maintaining a healthy weight, and reducing fatigue.

Exercise Recommendations

- Start Slow and Steady: Aim for small, consistent steps — even 10–15 minutes a day can make a difference.
- Mix It Up: Include a blend of:
  - Aerobic activity (like walking, swimming, or cycling)
  - Strength training (light weights or resistance bands 2–3 times per week)
  - Stretching and balance (gentle yoga, tai chi, or Pilates)
- Listen to Your Body: Fatigue is common with PBC — pace yourself and rest as needed.
- Stay Hydrated and Nourished: Drink plenty of water and maintain balanced nutrition before and after activity.

Always consult Your Healthcare Provider: talk with your doctor before starting or changing a diet or exercise routine, especially if you have advanced liver disease, joint pain, or fatigue.

Mindfulness

Relaxation techniques for PBC patients include the following steps:

- Deep breathing: Take a deep breath and focus on the present moment.
- Positive self-talk: Remind yourself that negative thoughts are just thoughts and let them go.
- Self-care: Do something nice for yourself, such as going for a walk, taking a bath, or spending time with loved ones.
- Muscle relaxation: Get into a comfortable position and relax your muscles.
- Imagery: Visualize a peaceful scene to reduce stress and anxiety.



Self-Care and Emotional Wellbeing with PBCare

Managing Primary Biliary Cholangitis doesn't just mean focusing on your liver, it also means caring for your whole self, including your mental health, relationships, and daily life. Here are some ways to support your emotional and physical wellbeing:

Stay Active, Gently

Even light movement—like a short walk or stretching—can help reduce fatigue, improve sleep, and ease feelings of anxiety or sadness. With PBC, you may feel tired often, so find activities that are manageable and restorative. It's okay to start small.

Reach Out for Support

Living with a chronic condition can be isolating. Talking to a friend, family member, nurse, social worker, or mental health provider can help. You are not alone. Consider joining a PBC or liver disease support group where you can connect with others who understand what you're going through.

Eat and Hydrate Well

A balanced, liver-friendly diet and staying well hydrated can help your body cope with stress and inflammation. Eating well can be tough when you're fatigued or feeling unwell. A registered dietitian can help you tailor meals that support your liver health without being overwhelming.

Make Time for Rest and Joy

Relaxation isn't a luxury, it's a necessity. Whether it's listening to music, meditating, enjoying nature, or taking a warm bath, do something each day that brings you peace. Keeping up with hobbies, family time, or light routines may help you feel connected to life outside of your illness.

Handle Practical Concerns Early

PBC can come with financial strain, job stress, or family pressures. If you're facing insurance or employment issues, consider asking for help from a social worker, patient navigator, or advocacy organization like the Community Liver Alliance. There are resources available.

Try Mind-Body Tools

Complementary practices like guided relaxation, meditation, yoga, or massage therapy may reduce stress and help with sleep or mood. Counseling can also help you process complex emotions or long-term adjustments.

Find Meaning in Your Own Way

Living with PBC may challenge your outlook. Some people find strength in their faith or spirituality, while others draw meaning from helping others or being in nature. Whatever brings you comfort—honor that part of your journey. Talking with a spiritual care provider, clergy member, or counselor can offer additional support.

Daily Journal

DATE

MOOD

YOUR THOUGHTS

GOALS

TO DO

Communicating with your Care Team

Living with PBC or any chronic condition can feel complex — but understanding how to communicate with your care team, ask the right questions, and manage your insurance can help you take charge of your health with confidence.

Good communication with your healthcare team helps you get the most out of every appointment. Here are a few ways to make your visits more productive:

- Be Open: Share all your symptoms, concerns, and changes — even if they seem small. Your doctor can only address what they know.
- Prepare Questions: Write down any questions before your appointment so you don't forget them. Keep a small notebook or use your phone's notes app.
- Bring Support: If possible, bring a family member or friend to help take notes or provide emotional support.
- Clarify Next Steps: Before leaving, make sure you understand your treatment plan, medications, and follow-up schedule.

Remember: You are the most important part of your care team. Speaking up and asking questions helps your providers support you better.

Questions to Ask Your Doctor

It's easy to feel overwhelmed at medical visits and having a list of questions can help you stay focused and confident. Consider asking:

- What are my treatment options?
- What should I do if my symptoms worsen?
- What symptoms should trigger a follow-up appointment?
- How often should I have follow-up tests?
- How often should I have follow-up appointments?
- Are there lifestyle or nutrition changes that could help my condition?
- Are there support groups or educational programs you recommend?

Tip: Write down your doctor's answers or ask for printed visit notes so you can review them later.

Ask Your Doctor Checklist

Use this checklist to prepare for your next appointment. Print it out and bring it with you to ensure all your important questions are addressed. There's space provided under each question to jot down your doctor's responses or any notes.

□ What are my treatment options?
Notes: _____
_____
_____

□ What should I do if my symptoms worsen?
Notes: _____
_____
_____

□ What symptoms should trigger a follow-up appointment?
Notes: _____
_____
_____

□ How often should I have follow-up tests?
Notes: _____
_____
_____

□ How often should I have follow-up appointments?
Notes: _____
_____
_____

□ Are there lifestyle or nutrition changes that could help my condition?
Notes: _____
_____
_____

□ Are there support groups or educational programs you recommend?
Notes: _____
_____
_____

Hand This to Your Doctor

If you've recently been diagnosed with Primary Biliary Cholangitis (PBC), you may find it helpful to share this page with your doctor or liver specialist. It can serve as a starting point for discussing your condition, treatment goals, and how to manage your health moving forward.

My Diagnosis

Primary Biliary Cholangitis (PBC)

- Date of diagnosis: _____
- Doctor who made the diagnosis: _____
- Current symptoms: _____
- Medications I'm currently taking: _____

Questions I'd Like to Discuss

□ What stage is my PBC, and how will it be monitored?
□ What treatment options are recommended for me?
□ Will I need regular liver function tests? How often?
□ Are there symptoms I should report right away?
□ Do I need to make any lifestyle or dietary changes?
□ What are my risks for complications like cirrhosis or fatigue?
□ Can I be referred to a liver specialist if I'm not already seeing one?
□ Are there clinical trials I should consider?

Tip

Bring a family member or caregiver with you to your appointments to help take notes and ask questions. You can also request a copy of your visit summary for your records.

Understanding Your Health Insurance

Navigating insurance can feel complicated, but keeping organized and asking questions can prevent surprises and stress.

Insurance Guidance:

- Coverage: Contact your insurance provider to confirm which treatments, lab tests, and medications are covered for your condition. Ask about prior authorizations if needed.
- Claims Management: Keep copies of bills, explanation of benefits (EOBs), and receipts for medical expenses. They can be helpful for reimbursement or tax purposes.
- Know Your Rights: If a claim is denied, you have the right to appeal. Your doctor's office or a patient advocate can often help with this process.
- Ask for Help: Many hospitals and liver clinics have financial counselors or patient navigators who can assist with insurance questions and applications for medication assistance programs.

Questions to Ask About Your Insurance and Coverage

General Coverage

- Is my current treatment plan covered under my insurance?
- Are there any preferred medications or providers in my plan's network?
- What is my annual deductible and out-of-pocket maximum?

Prior Authorization

- Does my treatment require prior authorization?
- Who submits the prior authorization—my doctor or the pharmacy?
- How long does it usually take to get approval?

Medication Access

- Is my prescribed medication on the approved formulary?
- Are there generic or preferred brand alternatives?
- What do I do if my medication is denied?

Diagnostic Testing and Lab Work

- Are liver function tests and imaging (like ultrasounds or MRIs) covered?
- Do I need to use specific labs or imaging centers?

Billing and Claims

- Can you help me understand a bill or Explanation of Benefits (EOB)?
- What should I do if a claim is denied?
- Can I set up a payment plan if I owe a balance?

Support and Appeals

- Who can I contact for help with an insurance appeal?
- Does the hospital or clinic offer a patient navigator or financial counselor?
- Are there any co-pay assistance or manufacturer savings programs available?

Tips for Family and Caregivers

Caring for someone with PBC is an act of love and commitment. As a caregiver or family member, your support plays a vital role in your loved one's health and quality of life.

Emotional Support

- Be patient and understanding: Living with a chronic illness can bring fatigue, frustration, or emotional ups and downs. Offer empathy, listen without judgment, and encourage open communication.
- Celebrate small victories: Recognize progress and positive moments, even small steps forward matter.
- Stay informed: Learn about PBC so you can better understand symptoms, treatments, and what your loved one may be experiencing.

Practical Help

- Assist with daily tasks: Help with chores, meal prep, or errands when your loved one is feeling tired.
- Transportation: Offer rides to medical appointments, support groups, or lab visits — this can ease stress and ensure consistent care.
- Organization: Help track medications, appointments, and test results using a Medication Tracker or Symptom Diary from the PBC Practical Tools Toolkit.
- Advocate together: Encourage your loved one to ask questions and express their needs during appointments or help take notes if needed.

Managing Caregiver Stress

Taking care of yourself is not selfish — it's essential.

Self-Care Strategies

- Prioritize your own health: Eat well, exercise, and make time for rest. You can't pour from an empty cup.
- Set realistic limits: You don't have to do everything. Ask for help and delegate when possible.
- Take breaks: Short moments of downtime — even 10 minutes of quiet — can help reset your energy.
- Stay connected: Keep in touch with friends, hobbies, and interests that bring you joy.

Support for Caregivers

- Join caregiver support groups: Sharing experiences with others who understand can provide relief, advice, and encouragement.
  - Family Caregiver Alliance – Education, support, and advocacy.
  - Well Spouse Association – Peer support for spouses and partners.
- Seek professional help: Talking to a counselor or therapist who understands chronic illness can help manage stress and prevent burnout.

Remember: You're not alone — support is available for caregivers, too.

Caregiver Resources

This resource guide provides caregivers with essential tools, support services, and practical advice to help manage the challenges of caring for someone with liver cancer. The links below direct caregivers to trusted organizations and resources for guidance, support, and self-care.

National Alliance for Caregiving (NAC)
www.caregiving.org

Family Caregiver Alliance (FCA)
www.caregiver.org

Caregiver Action Network (CAN)
www.caregiveraction.org

Global Liver Institute (GLI)
www.globalliver.org

Daily Strength: Caregiver Support Group
www.dailystrength.org

Healthy Caregiver Blog
www.healthycaregiver.com

Compassion & Choices
www.compassionandchoices.org

Advanced Care Planning
The Conversation Project
www.theconversationproject.org



Emotional and Mental Health Support
Psychology Today: Therapist Directory
www.psychologytoday.com

Mental Health America (MHA)

Practical Support and Financial Resources
LIVESTRONG Foundation
www.livestrong.org

NeedyMeds
www.needymeds.org

Partnership for Prescription Assistance (PPA)
www.pparx.org

Caregiver Self-Care Resources
Well Spouse Association
www.wellspouse.org

Aging with Dignity – Five Wishes
www.fivewishes.org

- Compassion & Choices
- www.compassionandchoices.org
- End-of-life care planning resources and legal support.



Support Information

The suggestions below may be a useful prompt when people say, "Let me know if you need anything."

Although family and friends are often eager to help, many people struggle to request and accept support. During treatment and while managing side effects, having a supportive network can be incredibly beneficial.

Family and friends generally welcome the opportunity to offer support, as it makes them feel helpful.

However, not everyone has family or friends who can provide the needed assistance. In such cases, numerous professional support resources are available to help.

People are often willing to help if they know what you need. Family and friends can support you in different ways. Some people will be able to talk about your diagnosis and comfort you if you are upset.

Other people may prefer to offer practical support. If you have a partner or another person providing most of your care, an important role for other family members and friends may be to support that caregiver.

Offering Practical Support

- Preparing meals
- Performing household chores
- Running errands and grocery shopping
- Driving to appointments
- Managing after-school schedules
- Assisting with exercise routines

Facilitating Communication

- Screening calls and emails
- Serving as the primary contact for family and friends
- Coordinating incoming support offers
- Managing updates on social media

Providing Companionship

- Spending time with you
- Listening empathetically without offering solutions
- Helping you stay active and social
- Engaging in conversations about topics other than cancer

Some people like to use an app on their smartphone or computer, such as Liver Education Advocates or Caringbridge. These resources allow you to choose activities that match your needs.

Advocacy and Involvement

Get Involved
Your voice and actions can help raise awareness, support research, and empower others living with PBC.

Advocacy Efforts:

- Join national or local awareness campaigns such as Delivering Hope or PBC Day.
- Share educational posts on social media to spread awareness about liver health.
- Participate in fundraising events that support research, patient education, and advocacy.

Volunteering:

- Partner with organizations focused on PBC and liver wellness:
  - Community Liver Alliance
  - PBCers National Organization
- Volunteer to help with community outreach, patient education, or event coordination.

Amplify your impact:

- Encourage your workplace or community to host a liver health awareness event.
- Share your story — personal experiences inspire others and highlight the importance of research and early diagnosis.

PBC research is moving forward every day, bringing new hope, improved treatments, and better understanding of this complex disease. By staying informed, advocating for awareness, and getting involved, you help shape a brighter future for everyone affected by PBC.

Join the Patient Registry
In partnership with CoRDS (Coordination of Rare Diseases at Sanford), the PBCers Organization has created a patient registry for Primary Biliary Cholangitis (PBC) to aid in research and treatments for people with PBC.

What Is A Patient Registry?
A registry is a place to store detailed information about people with a specific disease, syndrome or a group of diseases. When you enroll in a patient registry, you create your own personal health record. Your record, together with those of other PBC paties, forms a registry. Researchers can use registry information to search for commonalities, or to help identify those who may be eligible to participate in clinical trials. A patient registry can include blood and imaging test results, along with a patient's natural history (other medical conditions and symptoms).

Pharmaceutical Company Resources

IPSEN RESOURCES

GILEAD RESOURCES

DRUGS.COM



Financial and Medicare/Medicaid Resources

Medicare and Cancer: Surgery, Chemotherapy and Radiation (retireguide.com)

Senior Discounts & Benefits: Your 2023 Ultimate Guide (retireguide.com)

https://www.medicaidplanningassistance.org/getting-paid-as-caregiver/

Health Resources and Services Administration

Cost Plus Drugs

Good Day Fund

Healthwell Foundation

The Assistance Fund

Needy Meds

Find Help

RX Hope

Additional Resources

https://www.brightspotnetwork.org/support-groups/virtual-support-group-for-partners

https://www.cancer.gov/about-cancer/coping/caregiver-support

https://www.cancer.org/cancer/caregivers.html

https://www.aarp.org/caregiving/?cmp=KNC-BRD-MC-REALPOSS-BING-SEARCH-CAREGIVING&gclid=c3302ca10557110158b54afda2f363cc&gclsrc=3p.ds&msclkid=c3302ca10557110158b54afda2f363cc

https://www.bing.com/search?q=help+for+liver+caregivers&FPIG=D34E75570690400B99F24C8BBACA4D29&first=3&FORM=PERE

https://www.helpguide.org/articles/parenting-family/family-caregiving.htm

https://www.uptodate.com/contents/palliative-care-for-patients-with-end-stage-liver-disease/print

https://www.hepmag.com/basics/liver-health/caregivers

Clinical Trials

Clinical trials serve as the cornerstone for validating the effectiveness and safety of emerging treatments in securing regulatory approval. However, it has become increasingly evident that the underrepresentation of diverse patient populations in research studies has significant implications for health outcomes.

Advancing Health Equity with Clinical Trial Diversity
Clinical trials are currently the gold standard for proving the efficacy and safety of new treatments for regulatory approval. Data has revealed that underrepresented patient populations in research have impacted health outcomes.

If you're interested in participating in a clinical trial, talk to your healthcare provider about studies that may be appropriate for you based on your diagnosis, treatment history, and health goals.

Goals of the Clinical Trials Page

- To aid individuals in making informed decisions regarding participation in clinical trials.
- To educate the provider community about clinical guidance for their patients.
- To provide access to credible and up-to-date clinical trial opportunities.
- To promote links to member partners clinical trial opportunities.
- To promote health equity with clinical trial diversity.

Clinical trial diversity is a critical component of public health

Whether researchers submit a new drug to the FDA or providers use data for medical decision-making, data collection from a participant population that reflects the entire patient population is very important.

The CLA Clinical Trial website page hosts an informational video developed to educate patients and providers about the basic purpose and process of clinical trials.

The CLA strives to unite patients, providers and the health care industry

We influence the best possible care practices and develop new, scalable solutions for the fight against liver disease.

Additionally, downloadable Clinical Trials Educational Guides geared towards patients and a separate guide for providers as another resource.

For More Information on Clinical Trials Check Out These Links

PBC Clinical Trials

www.clinicaltrials.gov

https://communityliveralliance.org/clinical-trials/

https://communityliveralliance.org/wp-content/uploads/2023/06/Clinical-Guidelines-Patient.pdf

https://communityliveralliance.org/wp-content/uploads/2023/06/Clinical-Guidelines-Provider.pdf

https://communityliveralliance.org/wp-content/uploads/2023/09/Clinical-Trials-Spanish.pdf



PBC Patient Survey

This survey was developed to help us better serve our valued patients and caregivers.

COMMUNITY LIVER ALLIANCE ™
GLOBAL AWARENESS. LOCAL IMPACT.

COMMUNITY LIVER ALLIANCE™

GLOBAL AWARENESS. LOCAL IMPACT.

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412-501-3CLA (3252)

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