

# Support Services for Families Facing Liver Cancer

Webinar by the Hepatitis B Foundation and Blue Faery

Presented June 3, 2015 by Karla Pillote, MSN, CANP, and Andrea Wilson, MPW

Question and Answer Session

## If a person has a family history of liver cancer, should his or her family members get tested for liver cancer?

If you have a family history of liver cancer, it is important to discuss this with your health care team. Remember, you don't get screened for liver cancer unless you have a risk factor for liver cancer. So it's important to know the risk factors. Individuals with liver cancer who have chronic viral hepatitis B or C infection, which are major risk factors for liver cancer, should make sure their family members (including children of the patient) are tested for hepatitis B or C infection and are treated and monitored as needed to prevent progression to liver cancer, or to detect liver cancer at an early stage.

## What resources are available to help me pay for treatment?

- **Employee assistance programs**  
Some employers provide employee assistance programs that range from financial assistance to social work programs, help with child care, assistance with legal issues, and support for caregivers.
- **State/local assistance programs**  
Some states have programs that will provide financial assistance to caregivers to help them look after a family member with serious, potentially life-threatening conditions.
- **Cancer Financial Assistance Coalition** (<http://www.cancerfac.org>): a coalition of organizations helping cancer patients manage their financial challenges
- **Good Days** ([www.gooddaysfromcdf.org](http://www.gooddaysfromcdf.org)): helps qualified patients pay their insurance co-pays so they can get immediate access to prescription medications
- **Needy Meds** ([www.needymeds.org](http://www.needymeds.org)): a national non-profit organization that maintains a website of free information on programs that help people who can't afford medications and health care costs
- **Partnership for Prescription Assistance** ([www.pparx.org](http://www.pparx.org)): helps qualifying patients without prescription drug coverage get the medicines they need for free or at reduced prices
- **Patient Advocate Foundation** ([www.patientadvocate.org](http://www.patientadvocate.org)): provides patients with arbitration, mediation and negotiation to settle issues with access to care, medical debt, and job retention related to their illness

## Additional resources for families facing liver cancer

Many resources are available to families facing liver cancer. It's best to start by asking your health care team about the services available at the treatment center where you are receiving care. Other resources are listed here.

- **American Cancer Society** ([www.cancer.org](http://www.cancer.org))
- **American Society of Clinical Oncology** ([www.cancer.net](http://www.cancer.net))
- **CancerCare** ([www.cancercare.org](http://www.cancercare.org)): provides counseling, support groups, educational workshops, publications, financial assistance, co-payment assistance, and community programs
- **CaringBridge** ([www.caringbridge.org](http://www.caringbridge.org)): helps people create a free CaringBridge website in a time of need so that they can share updates, photos and videos, and connect with friends and family who care and want to help.
- **Hep B United** ([www.hepbunited.org](http://www.hepbunited.org)): a national coalition to address and eliminate hepatitis B, a serious liver infection that is the world's leading cause of liver cancer.

- **Liver-Onc: The Liver Cancer Support Group** ([liver-onc@listserv.acor.org](mailto:liver-onc@listserv.acor.org)): a list serve provided by the Association of Online Cancer Resources
- **Lotsa Helping Hands** ([www.lotsahelpinghands.org](http://www.lotsahelpinghands.org)): online Help Calendar where caregivers can create a care community to help with requests for support (such as meals for the family, rides to medical appointments, or just stopping by to visit)
- **MD-Junction-Liver Cancer:** (<http://www.mdjunction.com/liver-cancer>) : unmonitored online community of patients, family members and friends dedicated to dealing with liver cancer together
- **National Cancer Institute** ([www.cancer.gov](http://www.cancer.gov))
- **Yes! Beat Liver Tumors** ([www.beatlivetumors.org](http://www.beatlivetumors.org)): provides information, support, resources and hope for those affected by cancers of the liver

### Key Take-Aways

- Be an **advocate** for yourself because knowledge is power. If you cannot do it, find someone you trust who will advocate on your behalf.
- Always seek a **second opinion**.
- **Family members** and friends often want to help but don't know how. Give them specific tasks! Ask them for donations (even a small amount can help pay for parking or meals for the caregivers), or ask them to do research for you or come with you to appointments.
- Prepare an **advanced directive** (living will), which outlines your health care wishes if you are unable to speak for yourself.
- Appoint someone to serve as your **power of attorney**. This should be someone who will be the best possible advocate for you and will carry out your wishes. Keep in mind that sometimes that person is not your spouse or child.
- Ask your health care team if there is **another patient** in a similar situation who might be willing to talk to you. It can be helpful to talk with someone who has experienced or is experiencing the same issues as you.
- **Don't be shy!** Speak up! If you don't understand something, ask your health care team. There is no such thing as a stupid or irrelevant question when it comes to your health care.
- Ask for instructions and information to be given to you **in writing**, so that you can review again once you get home or share with family and friends.
- **Take notes** or ask someone to come with you to appointments to take notes and ask questions.
- Ask your health care team whether the cancer center provides **information sessions** for patients and caregivers. Also ask about **other support services** that you might need (for example, translation services, social worker assistance, help with insurance or legal issues).
- Find out what your insurance will cover. **Read through your insurance policy carefully** and ask about anything you don't understand. Be sure to find out what costs you are responsible for and whether your doctors are covered by your insurance plan.
- Ask your insurance company if you can be assigned a **case manager** to help you navigate your insurance coverage issues.
- If you don't have insurance, talk to your health care team and the hospital financial services department and your local department of health. **Find out what benefits you may be eligible for** and apply for those.