

Risk factors for financial hardship include current low income or financial hardship, being a single parent, living a long way from your child's treatment center, anticipating a long or difficult course of treatment, or having a job that is insecure or inflexible. So if you are in or find yourself moving into any one of these categories or even if there is a remote likelihood that you could down the road, what can you do?

- 1.** Ask to meet with a resource specialist or social worker at your child's hospital immediately. He or she should be able to help you access concrete resource support such as assistance with parking fees, utility bill payments, or grocery cards. Many families are eligible for assistance from federal or state programs and/ or philanthropic foundations or societies. Some funds are available based on the child's particular conditions—for example, from the Pediatric Brain Tumor Foundation, the Jeffrey Modell Foundation (for immune deficiency disorders), or the Wiskott-Aldrich Foundation (for Wiskott-Aldrich syndrome). Others have somewhat broader eligibility criteria such as the National Children's Cancer Society, the Bone Marrow Foundation, or the Family Reach Foundation. Others are more need- based than condition-related, such as the Patient Advocate Foundation, the National Patient Travel Center, or Next Step, or government- funded programs such as Medicaid, Supplemental Security Income (SSI), and the Women, Infants, and Children program (WIC). Please note that the availability of funds at philanthropic foundations as well as their eligibility guidelines varies widely, so the guidance of a knowledgeable resource specialist or social worker can be a tremendous help. (See Appendices A and B.)
- 2.** If you are a single parent, ask the hospital staff if they have funds available specifically for those without partners.
- 3.** Your resource specialist/ social worker may also have access to hospital donor funds that are specifically earmarked for resource assistance. Hospitals that do provide this assistance are not allowed to advertise it, because it could be seen as a way to attract patients, but you should not be afraid to ask. For example, each year the resource specialists in the Pediatric Resource Program at Dana- Farber are able to help ontreatment families access \$850,000 in support; this includes \$400,000 from a variety of philanthropic foundations along with \$450,000 from hospital donor funds earmarked for resource support. In addition, the program helps families access significant amounts of additional resources from several external sources that are difficult to track. This includes SSI payments, Premium Assistance payments, and savings through supplementary Medicaid coverage.
- 4.** Seek out other parents or join a parent group in the hospital. Other parents are happy to share information on accessing extra financial resources and how to cope with income loss.
- 5.** You can search the Web to see if resources from local, state, federal, or private sources could be available to compensate for a serious income loss or to address a particular financial stressor like an overdue rent payment. Try not to wait too long, because some of the organizations or agencies that do have funds available may take some time to process your request.
- 6.** Consider whether you can temporarily adjust your budget in ways that would economize but not cause your family significant hardships, such as postponing planned expenses or buying generic brands. If you are already struggling financially, any further economy may be a significant hardship.
- 7.** Although it may be difficult to accept the generosity, try to be grateful, not reluctant, should family, friends, or neighbors want to organize a fund- raising event for your child, be it an auction, a raffle, a sports event, or a yard or bake sale. It will help you and they will be glad to have something useful to do.

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8. Similarly, try to be grateful, not reluctant, should colleagues offer you some of their vacation time to be sure you can have your time out of the office paid.

9. Advocate for some flexibility in your work schedule and be sure to explore your eligibility for time off via the Family Medical Leave Act. How your employer reacts to the situation has a big impact. Employers vary greatly in their responses, and some jobs allow more flexibility than others. We found some employers were enormously sympathetic and translated their concern into allowing modified work schedules, time off as needed, and a guaranteed return to the same job when circumstances allowed it. Others were more rigid and had strict rules about family and sick leave. In a two-parent family, parents sometimes decided who would work and who would not, based on the relative flexibility of each job and employer and who carried the family health insurance. Single parents faced a particularly hard challenge when faced with an inflexible employer. Whatever your employment situation, the medical and psychosocial staff will help in whatever way they can. You may ask them to write a letter to your employer to describe your child's diagnosis and the treatment and extent of hospitalizations your child may need. They can also describe additional expenses you are likely to incur. If useful, a psychosocial clinician would likely be happy to add a supporting letter that describes in more detail the emotional burden of the treatment on your child and the importance of your presence at certain, often unpredictable, moments.

10. Advocate for and participate in periodic assessment by your psychosocial clinician or a researcher of your current financial situation during your child's treatment. The more financial hardships are documented (either already existing or precipitated by your child's treatment) and the greater providers' understanding of how they correlate with health outcomes for the children, the more caregivers will advocate for additional resources to be made available to compensate for those losses. Some researchers are already advocating that financial hardship be considered as a risk factor along with certain biological markers in designing an appropriate treatment plan for a particular child.