



My son is only 14, why should I return the Pregnancy Survey?

Many of you have asked us this question. Some parents do not understand why we are asking for this information for children under 18 years of age. Pregnancies are occurring at ever younger ages. Also, some young men think this is a question only for young women, although adolescent males have become fathers. Others think that there is no reason to return a survey when they have never been pregnant or fathered a child. Some parents believe it is irrelevant because their child is a young teenager. Have you perhaps not returned the survey because you had similar thoughts? If yes, please reconsider.

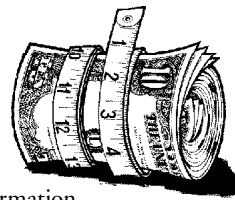
For our study of pregnancies it is important that we hear from as many participants as possible, both men and women. If we send out 4000 surveys and only 2000 are returned, we do not know what it means if 500 pregnancies are reported. The simple calculation is $500/2000=25\%$. Should we then believe that 25% of participants have had a pregnancy? If we did, we would

be wrong. It is just as important for us to hear from female participants who have not become pregnant and male participants who have not fathered a child.

Preliminary information showed us that almost all survivors of Wilms tumor are capable of becoming parents. We are currently updating this study and need everyone's help in order to confirm that the earlier information continues to be true. Many of you have contacted us with questions about fertility and pregnancy. We very much want to answer these questions, so we need everyone's help to gather that important information. If you haven't returned the pregnancy survey, please do so as soon as possible. If you have lost your survey please contact us on our message line, 1-800-553-4878, and we would be happy to send you another one. Your participation in this aspect of the study will be invaluable. Thank you to those of you who have returned the survey. Your help is greatly appreciated. ❏

What To Do If You're Uninsured

By: Gib Smith, JD – Director, Childhood Cancer Ombudsman Program and Grace Monaco, JD – Director, Managed Care Ombudsman Program



Access to care is compromised when the family is uninsured. What can the medical care team do to help cancer patients/survivors and their families find health insurance? This is a real and constant problem in the cancer community. It is tough enough trying to recover from radiotherapy and chemotherapy without having to worry about how to pay for these necessary treatments. This article attempts to provide a brief overview on some of the resources and protections available to those affected by a diagnosis of cancer.

If you don't have, have lost or are looking for insurance coverage we can suggest the following resources/options:


- Call your County Welfare Office and ask for information about applying for Aged, Blind, Disabled Medically-Needy Medicaid for your child. If you meet the income and asset limits your child can be put on Medicaid.
- While on the line with the welfare office they should check on the State Children's Health Insurance Program (SCHIP). In 1997 the SCHIP Program gave the states new federal funds to expand children's health coverage programs, which led to a dramatic extensions of coverage for low-income children through Medicaid and separate SCHIP programs. There is some form of SCHIP in the 50 states and the District of Columbia.
- An underutilized, but excellent source of information regarding local resources is the social worker in the pediatric oncology clinic. For example, in some facilities Social Security employees come to the hospital periodically to help families apply for benefits. The social worker should have contact information so you can apply for the right welfare programs.
- Check on resources of your State's Childrens Medical Services Program. Some families who don't qualify for Medicaid may qualify for assistance to pay for needed care under that program if the family income level is below their coverage income level.
- Consider the Health Insurance Portability and Accountability Act (HIPAA), which allows those with preexisting conditions to secure comprehensive health insurance coverage. From the parents' perspective, HIPAA also helps people maintain their coverage if they need to change insurance or jobs. For more information regarding HIPAA visit <http://cms.hhs.gov>.
- Finally, the Consolidated Omnibus Budget Reconciliation Act (COBRA) mandates that both

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public and private employers with twenty or more employees or greater than 50% of the working days in the previous calendar year must make insurance coverage available for a limited period of time to employees and their dependents. Under COBRA, employees who have been fired or laid off have a right to continue their group health coverage at their own expense at no more than 102% of their employers' group rate. For those individuals with disabilities the coverage period can be extended to 29 months in certain situations. For further information regarding COBRA, contact the Pension and Welfare Benefits Administration at the United States Department of Labor.

This list is intended to be a reference for you and your medical care team. Just having this information and the willingness to share it may save patients and their families hours of anguish, additional out-of-pocket costs, and perhaps lives if successful in obtaining some form of coverage for expensive cancer treatments that would otherwise not be covered.

NOTE TO OUR CANADIAN PARTICIPANTS:
Similar information is being gathered for our Canadian participants and will be posted on our web site prior to the publication of the next newsletter. 

Meet the Late Effects Study Staff

Bobbi Benson began her work with the Data and Statistical Center (DSC) seven years ago. She first conducted interviews for a study of cancer in families funded by the American Cancer Society. Results of this study were released just last year. Bobbi then coordinated registration for the Risk Factor Study, a study that evaluates the relationship between occupational, environmental and other suspected risk factors and the occurrence of Wilms tumor. Currently she works to document "targeted" late conditions, an important aspect of the Late Effects Study.

Targeted conditions identify certain late conditions former Wilms patients may have had as a result of

treatment for Wilms tumor. These conditions are second malignant tumors, congestive heart failure or cardiomyopathy, respiratory failure and/or renal failure. Bobbi ensures all steps in documenting the onset of a targeted condition are met. This process can take some time as well as follow-up calls and letters to participants,

their families and to doctors and hospitals. The information we gather on these conditions will enable us to advise people who were treated for Wilms tumor about what tests to have done so they can be treated at an early stage, if they develop.


What inspires Bobbi most about working with the Late Effects Study is "The possibility that the results of my work will benefit children." Bobbi says, "I really enjoy talking with participants on the phone and I hope that my work, combined with the work of all my colleagues, will contribute towards learning more about what causes Wilms tumor, so one day, we might know more about how to prevent it."

Bobbi's favorite activity is traveling with her family. Several times they have had the opportunity to travel for a couple of months and because her children were only 3 and 5 years old when they started traveling, they would rent cottages and try to live as much as possible like local families. One time, this included having both of her children come down with chicken pox in England. During these trips they love to hike, be it through Capadocia in Turkey or the fjords of Norway. Most recently Bobbi was in Vietnam where she especially loved walking in the mountains around Sapa, a small village near the Chinese border. Bobbi also enjoys cross country skiing, cooking and reading.

Sarah Christie has been working for Fred Hutchinson Cancer Research Center (FHCRC) for three years and in March, 2002 joined the DSC. She coordinates all of the pregnancy correspondence for the Late Effects Study and contacts participants to conduct phone interviews. Previously with Collaborative Data Services (CDS) at FHCRC, she interviewed participants on various cancer prevention studies and then moved on to supervising other CDS interviewers.

Sarah says one of her favorite things about working for the Wilms Tumor Study is speaking with participants on the phone. "It's great to hear the excitement in a mother's or father's voice as they tell me about their new baby. I also hear some sad stories and am always amazed by the strength and positive attitudes these participants have despite going through some very hard times."

Although she loves Seattle's energy, water and mountains, she still maintains a very close tie to her hometown Milwaukee, Wisconsin, where she tries to visit once or twice a year to catch up with family and friends.

Sarah enjoys spending her free time practicing yoga, rollerblading and camping (weather permitting). She is also a great fan of the movies and actively sings in a choir. Recently she even recorded a song that was featured at her friend's wedding. Perhaps when you speak with her on the phone you can guess which 1972 Seals and Croft hit it is! 



Bobbi & Sarah