

SurvivorLink: An Invaluable Tool for Survivors of Childhood Cancer

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Survivors of childhood cancer can be at risk for health problems after cancer treatment which are called late effects. All survivors should visit a childhood cancer survivor clinic when they are two or more years off treatment. During this visit, survivors will get a Survivor Healthcare Plan (SHP) which includes 1) information about the survivor's cancer diagnosis and treatment, 2) a list of late effects that can occur after his/her treatment and 3) a list of tests needed to screen for those late effects.

It is helpful for all of the survivor's healthcare providers (doctors, nurses etc.) to have access to the information in the SHP. Some healthcare providers are not familiar with the types of late effects that can happen after childhood cancer treatment. Being able to share the SHP will help the survivor communicate with his provider about the types of health problems he is at risk for.

Researchers from Emory University, doctors and nurses from the Aflac Cancer Center at Children's Healthcare of Atlanta and engineers from Georgia Institute of Technology and HIMformatics, LLC worked to create the SurvivorLink website (www.cancerSurvivorLink.org). This website is designed to help survivors of childhood cancer share information about their cancer treatment and risk for future health problems with their healthcare providers. SurvivorLink is a safe and secure place for survivors to store their health records online.

SurvivorLink is designed to have the parents/guardians of children who are still under 18 register and use this site. If the survivor is 18 years of age or older, the survivor herself will register to use this site. Register for SurvivorLink by visiting the Patient and Families section of the website. You will see a 'Getting Started on SurvivorLink' page which will give you step by step directions on creating a patient chart.

Once registered, survivors (or parent if the survivor is under 18) can grant permission to their healthcare providers to view their health records on the website which will help their providers

understand their cancer diagnosis and treatment. Only health care providers who are invited by the survivor (or parent if the survivor is under 18) will be able to view health records on SurvivorLink. No one will be able to view the survivor's records on SurvivorLink unless approved by the survivor (or parent if survivor is under 18).

The SurvivorLink website includes information for survivors and families about finding a survivor clinic, health insurance, and educational information about each late effect. There are links to other websites which may be helpful resources for survivors and their families. SurvivorLink also has educational information for healthcare providers to learn more about late effects of childhood cancer treatment. Providers can earn continuing education credits by reading text modules or watching a lecture as a video. Survivors should encourage all of their healthcare providers to register for SurvivorLink. The healthcare provider must be registered on SurvivorLink in order to receive an invitation to view a survivor's record.

All pediatric cancer survivors in Georgia are being recruited to use the website. The five pediatric cancer centers in Georgia are part of the SurvivorLink project. Some of you may have received a packet in the mail encouraging you to visit and use the website. If you did not receive a packet in the mail about SurvivorLink you can still register and use all parts of the SurvivorLink website. If you have any questions about registering for SurvivorLink, you can contact us through the website using the 'Contact Us' tab, or through the SurvivorLink contact number at 404-785-1911.

Survivors of Childhood Cancer

If you are a survivor of childhood cancer please visit the site, register and create a SurvivorLink health record. SurvivorLink is a place for you to store your SHP and any other health documents. By saving your SHP on SurvivorLink you won't have to worry about losing the copy that you get from your survivor clinic.

Your health care provider can view your most recent SHP online so you won't have to bring them a new copy. If you see a new doctor, you can allow them to view your SHP on SurvivorLink so they can quickly learn about your medical history.