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The National Children’s Cancer Society Endorses New Standards of Psychosocial Care for Children with Cancer

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The National Children’s Cancer Society (NCCS) has endorsed the new publication, Standards of Psychosocial Care for Children With Cancer and their Families, for highlighting many of the needs of families facing pediatric cancer – needs that the organization has made it a mission to meet since 1987.

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The National Children’s Cancer Society (NCCS) has endorsed the new publication, Standards of Psychosocial Care for Children With Cancer and their Families, for highlighting many of the needs of families facing pediatric cancer – needs that the organization has made it a mission to meet since 1987.

The publication offers the first national standards for the psychosocial care of children with cancer and their families. The standards, published in the journal “Pediatric Blood and Cancer”, are a road map for health-care providers from the moment of diagnosis into survivorship or bereavement. They were developed at the urging of parents Vicki and Peter Brown based on the issues they faced during the years their only son fought a battle with bone cancer, which he ultimately lost.

The standards address many care issues needed by families and stress the value of psychological, emotional and social support as being just as important, if not more important, than medical treatment.

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Of particular interest to the NCCS were needs assessments of the financial burdens placed on families whose children have cancer, the critical role of psychosocial care for parents of children with cancer, and similar care needed for pediatric cancer survivors as they move into adulthood.

“Our mission at the NCCS is to provide emotional, financial and educational support to children with cancer, their families and survivors,” said Mark Stolze, president and CEO of the NCCS. “All our programs have been developed with their immediate and long-term support needs in mind. The new Standards state what we’ve experienced firsthand as we’ve worked with families for all these years – that the psychosocial needs are critical to address in order to keep the child and the entire family as healthy as possible.”

Among the programs the NCCS provides to meet the psychosocial needs of children with cancer and the families are:

Financial assistance for transportation and lodging and meals for parents during a child’s treatment in a hospital away from their home.

A Family Support Program that provides a caseworker to journey alongside the family during and after treatment. The NCCS proudly states that it offers children and survivors a case manager for life.

Information to help parents with the educational challenges their child may face while undergoing treatment, and learning disabilities that may occur as a result of treatment drugs.

College scholarships for young adult survivors.

Conferences throughout the country addressing the myriad psychosocial, lifestyle and medical issues faced by survivors.

A mentoring program that pairs young adult survivors with children currently going through cancer treatment, offering them friendship and encouragement from someone who understands their challenges first-hand.

Parents have specific challenges, said Jessica Cook, coordinator of Patient and Family Services for the NCCS. They must be strong and positive for their sick child, but at the same time find a way to cope with their own distress and fear about their child’s diagnosis.

“Being told that your child has cancer launches most parents and family members onto an emotional roller coaster,” said Cook. “Parents are greatly helped by having knowledge and people around them – doctors, nurses and other professionals – who will answer their questions accurately and honestly.”

The Standards of Care emphasized the need for parents and caregivers to receive early and ongoing assessment of their mental health needs, and be provided access to appropriate interventions. The NCCS case managers assist in that process by referring families to appropriate services.

Survivors also have very specific needs, said Pam Gabris, coordinator of the NCCS Beyond the Cure survivorship program. Most survivors have a high risk of medical late effects following cancer treatment, yet many do not receive screenings for late effects or long-term follow-up care. The NCCS offers a late effects after-treatment tool on its website, which provides a personalized assessment of their late effects risk. The organization also connects survivors to resources that can help them with educational challenges, career development and long-term health care monitoring.

Ultimately, Stolze said, it is hoped that the new Standards will help everyone who works with children with cancer provide better services and support to the entire family.

About The National Children’s Cancer Society
The mission of The National Children's Cancer Society is to provide emotional, financial and educational support to children with cancer, their families and survivors. To learn more about the NCCS and its support services, visit thenccs.org. The National Children’s Cancer Society is a 501C(3) organization that has provided over $62 million in direct financial assistance to more than 38,000 children with cancer. To

contact the NCCS, call (314) 241-1600. You can also visit the NCCS on Facebook.

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