



Approved August 25, 2011

FAMILIES OF CHILDREN

With Holoprosencephaly

Researchers at the Kennedy Krieger Institute Carter Center are trying to learn more about the health-related quality of life of children with holoprosencephaly (HPE) and other severe brain malformations. Through this and other studies, we hope to improve care and measures of treatment effectiveness in these children and their families. If your child has **HPE** or a related brain malformation, and is **2 through 17 years of age**, you are invited to participate in this research study. The study does not require a clinic visit and can be completed using a computer in your home or elsewhere. The online survey usually takes about 30-40 minutes to complete.

If you are a parent of a child with HPE between the ages of 2 and 17 years, we invite you to go to [HPE QOL Study Online Survey](#) and enter survey # 142958. We thank you very much for being willing to help us and other individuals with HPE by participating in this study!

For more information or to see if you are eligible to participate, contact Dr. Stashinko at:

443-923-9146 or 800-873-3377 ext. 9146
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RPN: NA_00048645 The reliability and validity of the CPCHILD© in children with holoprosencephaly (HPE) or a related brain malformation.

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