

Sickle Cell Disease Treatment Demonstration Program

Your child is being asked to take part in a research study. This consent form tells you about the study and the type of information that will be asked of you and your child. You can choose to have your child take part in the study or not. If you permit your child to take part, you will need to sign this form. Your child will also have a consent form to read or have read to them and sign.

Your child's doctor/clinic is participating in a study conducted by RTI International. This project is funded by the U.S. Department of Health and Human Services, Health Resources and Services Administration's Maternal and Child Health Bureau (HRSA). This project is taking place at four locations across the United States and about 400 adults and children will take part. The study is designed to learn about the experiences of patients enrolled in the Sickle Cell Disease Treatment Demonstration program.

If you agree to let your child be in this study, you and your child will be asked to provide some information when you are first enrolled and again one year later. The questions regard your child's health and health care. It will take 30 to 45 minutes to complete the questions. You and your child do not have to answer any questions you or he/she do not want to answer. No names will appear on the forms. If you decide to fill out the forms, you and your child can stop at any time. If you decide that your child will not take part in the study, it will not affect the health care your child gets from this doctor/clinic.

[You may not be able answer all the questions we ask or we may need to verify what you told us. When that happens we will need to check your medical record. The kinds of information we would be getting from your medical record would be things like the timing and number of hospital and medical visits and the kinds of treatments and vaccinations your child received.](#)

[By signing this form you give your provider \[INSERT NAME AND ADDRESS\] permission to release health information about your child to RTI International. This authorization expires on September 30, 2010. You may revoke this authorization at any time by notifying \[NAME OF THE LOCAL SCDTDP\] in writing.](#)

There are no direct benefits to you or your child for taking part in this study. By providing this information, you will help to answer questions about the sickle cell treatment model that we are studying. All of the information and comments that you and your child share with us will remain private [to the extent allowed by law.](#)

If you have any questions, please ask us. If you have questions later, please call RTI at (301) 230-4677. If you have questions about your rights as a participant in research, call the RTI Institutional Review Board Chair at (xxx) xxx-xxxx.

I agree to participate and to allow my child _____ to take part in this research study.

Parent/Legal Guardian Name (print)

Parent/Legal Guardian Signature/Date

Parent Consent Form for Minor Child
Draft version - not reviewed by IRB.