Rady Children's Hospital San Diego

Rady Children's Hospital—San Diego
3020 Children's Way
San Diego, CA. 92123

PATIENT INFORMATION

University of California, San Diego and Rady Children's Hospital
Authorization for Use and Disclosure of Protected Health Information for Research Purposes

Investigation of Sudden Unexplained Death in Childhood

You are being asked to be part of a research study under the direction of Dr. Henry Krous and his research team. The purpose of this study is to increase understanding of the characteristics, circumstances surrounding death, medical histories and pathology of children from ages 1 through 16 years who died suddenly and unexpectedly.

By signing this document, you give your permission to the Principal Investigator, co-investigators, study coordinators, and other members of the research team, as well as the pathologist who autopsied your child, to use and disclose the following information about you, your family and/or your child for research purposes:

- Information you provide in the family survey (if you choose to complete it)
- Information in your child's medical records and prenatal records including laboratory test results, and x-ray readings etc.
- Information in the medical examiner or coroner records and specimens

If you do not sign this authorization, you will not be part of the study.

This authorization has no expiration date.

You can withdraw your authorization at any time. To withdraw your authorization, you can write to Dr. Henry Krous or you can ask a member of the research team to give you a form to withdraw your authorization. If you withdraw your authorization, you will not be able to continue to be part of the study.

If you withdraw your permission, Dr. Henry Krous and his research team can continue to use information about you, your family, or your child that has already been collected in order to maintain the integrity of the study. No information will be collected after you withdraw your permission.

As part of this study, we also may disclose your and/or your child's information to the Department of Health and Human Services Office for Human Research Protections, Office of Civil Rights, the Food and Drug Administration and other federal or state agencies responsible for the oversight and conduct of research. Any information disclosed to these agencies may no longer be protected under federal or

state law. However, other laws, regulations and agreements may protect the information from improper use or disclosure.

This study includes the creation of a database of information gathered from the evaluation of records and specimens (e.g. blood, tissue, or other bodily fluids) that may be used in future research. By signing this authorization, you agree to allow the information collected in this study to be added to that database for future use.

Rady Children's Hospital and University of California San Diego comply with all applicable laws that protect your privacy. We will protect your privacy according to these laws. Despite these protections, there is a possibility that your information could be used or disclosed in a way that will no longer be protected.

By signing this authorization, you agree that you have read this form and have been given the opportunity to ask questions. If you have questions later, you can contact Research Associate Elisabeth Haas, MPH at ehaas@rchsd.org or 858-966-5944.

You give permission for your child's prenatal and postnatal medical records and postmortem examination results to be released from:

______________________	______________________
Medical Examiner/Coroner's Office	Physician/Medical Office
______________________	______________________
Physician/Medical Office	Physician/Medical Office
______________________	______________________
Physician/Medical Office	Physician/Medical Office

You give your permission for the use and disclosure of your child's health information as described in this form.

______________________	__________
Printed name of Participant	Date of Birth
______________________	__________
Signature of Participant	Date
______________________	__________
Signature of Person Who Explained This Form	Date