

WHO DO I CONTACT FOR MORE INFORMATION?

Judy Kurtz, SDY Project Coordinator
(757) 785-3156

THIS PROJECT IS SUPPORTED BY:

Centers for Disease Control and Prevention
National Institutes of Health

FOR MORE INFORMATION ABOUT THE SDY CASE REGISTRY:

www.sdyregistry.org

AGENCIES WORKING ON THE REGISTRY

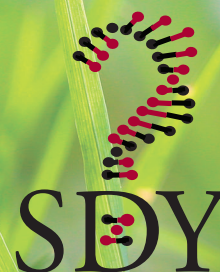
Virginia Department of Health,
Office of the Chief Medical Examiner
Eastern Region Child Fatality Review Team
Sudden Death in the Young Advanced
Clinical Review Team

INFORMATION FOR FAMILIES

THE SUDDEN DEATH IN THE YOUNG CASE REGISTRY

WORKING TO COUNT,
UNDERSTAND, AND
PREVENT SUDDEN
DEATH IN THE YOUNG

Data Coordinating Center for the
Sudden Death in the Young (SDY) Registry
Telephone: 800-656-2434
Email: info@SDYregistry.org



DATA COORDINATING CENTER FOR THE
SUDDEN DEATH IN THE YOUNG
CASE REGISTRY

RESOURCES

BEREAVEMENT SUPPORT GROUPS

The Compassionate Friends (Non-Profit National Org.), compassionatefriends.org, 877-969-0010

MISS Foundation (Non Profit International Org.)
missfoundation.org, 888-455-6477

REGION SPECIFIC BEREAVEMENT SUPPORT GROUPS

The Compassionate Friends- Tidewater Chapter
tcftidewater.org, monthly support group for adults
Virginia Beach, contact: Maureen & Bill Harman
757-484-8161

The Compassionate Friends- Peninsula Chapter
monthly support group for adults, Yorktown
contact: Felicia Johnson 757-384-0823

Children's Hospital of the King's Daughters
chkd.org, monthly support group for parents, Norfolk
contact: Linda Baynes 757-668-8246

Bon Secours Bereavement Center
bonsecours.com/richmond/our-services/hospice/bereavement-services, monthly support groups
for adults and children, Newport News
contact: Shannon Renfro 757-310-7030

Edmarc Hospice for Children
edmarc.org, monthly support groups for adults
and children, Portsmouth and Norfolk locations
contact: Sarah Zandford 757-967-9251

FAMILY MEDICAL FOLLOW-UP

If heart disease is identified as cause of death
or if death remains unexplained

**Pediatric Cardiology at Children's Hospital
of the King's Daughters**, Norfolk, Virginia
757-668-7214

**Pediatric Neurology at Children's Hospital
of the King's Daughters**, Norfolk, Virginia
757-668-9920

SPECIFIC SUPPORT GROUPS

Sudden Unexplained Infant Death (SUID)/
[Sudden Infant Death Syndrome \(SIDS\)](#)

CJ First Candle Foundation, cjfirstcandle.org
[Heart](#)

Hypertrophic Cardiomyopathy Association
4hcm.org

Parent Heart Watch, parentheartwatch.org

**Sudden Arrhythmia Death Syndrome (SADS)
Foundation**, sads.org

[Epilepsy](#)

Epilepsy Foundation SUDEP Institute
epilepsy.com/get-help/about-sudep-institute

The Danny Did Foundation, dannydidd.org

Citizens United for Research in Epilepsy (CURE)
cureepilepsy.org/research/sudep.asp

WHAT KIND OF INFORMATION IS THE SDY CASE REGISTRY COMPILING?

The Sudden Death in the Young (SDY) Case Registry gathers information to learn more about children who die suddenly and unexpectedly. The project is funded by the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC). The SDY Data Coordinating Center located in Michigan is working to implement the SDY Case Registry.

The purpose of the SDY Case Registry is to try to understand the cause of these deaths and find ways to prevent these deaths.

You may be contacted in the future to consent to save your child's DNA and/or be re-contacted as part of the SDY Case Registry.

The SDY Case Registry is compiling information from the autopsy and death scene investigation, DNA from samples obtained at the time of autopsy and medical history of the child and the child's family. All of the information gathered for the SDY Case Registry will be kept confidential and private.