Join Us at the Inaugural SUDC Family Retreat
October 26 to 28, 2018, in Naples, Florida

The first-ever SUDC Foundation Family Retreat will take place at the Naples Grande Resort, in Naples, Florida, from October 26 to October 28, 2018. The weekend will focus on wellness, mindfulness/meditation, bereavement, and education. The retreat seeks to bring together families affected by SUDC, for the unique support provided by those who share similar experiences and for the opportunity to learn new coping tools from guest speakers.

Cultivating meaningful connections among bereaved families is a cornerstone of the support offered by the SUDC Foundation and is crucial to our mission. Last year, the first-ever SUDC Medical Conference at NYU Langone Health in New York City brought together the largest group of family survivors of SUDC. The family retreat aims to be even bigger.

“For anyone who attended the SUDC Medical Conference last May in New York, we know how impactful and comfortable it felt to be among families who know what only we know,” said Steve Myers, SUDC Foundation Board Member and SUDC parent. “There was a feeling of warmth, compassion, and understanding that just doesn’t exist in any other setting or with any other group. I remember the comfort I felt and the comfort I sensed from others in being able to speak freely about our children in an environment where there was no judgment and no societal norms that we had to follow.”

With the help of private donations to the SUDC Foundation, the retreat activities will be complimentary for all participants. Sponsorships are also available. Please visit sudc.org/familyretreat for more information.

Each day, the retreat will offer restorative activities and workshops crafted specifically for parents who have suffered the loss of a child. Age-appropriate activities for siblings are also scheduled.

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Dear Reader,

The SUDC Foundation is proud to share our accomplishments, news, and resources with you in this newsletter. As a community of families, professionals, and donors, we are all advocates reaching for a brighter future for all children and their families. Thank you so much for your dedication to our dear cause.

Due to the support we receive from private donations, we are able to provide all our services at no cost to those who need us. We often think of SUDC families in crucial need of information, advocacy, and emotional support. To improve our family services, we have now streamlined our registration process to provide quicker and easier access to the comprehensive services available to them.

We also recognize that professionals are in vital need of our support, too. Especially in these times of an opioid epidemic, the same professionals investigating the tragedies of SUDC are also having their time and resources overwhelmed by the pressures of our society overall.

Advocacy services at the SUDC Foundation and resources at the SUDC Registry and Research Collaborative are vital in our coordinated effort to help grieving families, perform high quality investigations, and intensify crucial research.

Thank you again for your support,

Laura Gould Crandall,
President and Executive Director

SUDC Awareness Month Reaches New Heights

March 2018 marked the third year of SUDC Awareness Month activities. We are proud to announce that 43 states joined our nationwide effort and proclaimed March as SUDC Awareness Month.

In addition, 3,000 people changed their Facebook profile pictures to spotlight SUDC awareness. Each week, the SUDC Foundation’s public Facebook, Twitter, and Instagram pages announced a new activity and encouraged the SUDC community to share their stories of participation on social media with #SUDCawareness.

We had very high participation in our month-long activities, which included wearing SUDC memorabilia, performing random acts of kindness, sharing information about SUDC, and posting videos on social media about why SUDC Awareness Month is so important.

Thank you for joining us in a very successful month to shine a light on SUDC and promote awareness!
Amazing Start for SUDC Ambassador Program

In January of this year, we launched the SUDC Foundation Ambassador Program. The Ambassador Program is the Foundation’s formal volunteer initiative created to empower SUDC families and other members of the SUDC community to promote awareness and support the mission of the Foundation.

We are pleased to announce that we have already enrolled and trained over 60 ambassadors across the United States, Canada, Australia, and Europe, filling the roles of fundraiser host ambassador, event representative ambassador, social media advocate ambassador, information table host ambassador, family gathering host ambassador, and peer support volunteer ambassador.

This summer, we will begin training for our ambassadors interested in the roles of medical speakers bureau ambassador, general speakers bureau ambassador, policy advocate ambassador, and media spokesperson ambassador.

The SUDC Ambassador Program aims to:

• Leverage our growing community worldwide
• Create an army of advocates to support the organization
• Show the many faces and voices of SUDC
• Support consistent messaging for SUDC to strengthen our ability to raise awareness
• Allow the SUDC Foundation to participate in more outreach efforts
• Improve local awareness efforts
• Strengthen connections among the SUDC community
• Assist SUDC Foundation volunteers already performing similar duties

We truly appreciate our ambassadors’ dedication and support. To learn more about the SUDC Foundation Ambassador Program, please visit www.sudc.org/advocacy/ambassador-program or email ambassadorprogram@sudc.org.

Board of Director Announcement

We are pleased to announce the appointment of Steve Myers to the SUDC Foundation Board of Directors. Steve has a bachelor’s degree in Psychology from Princeton University in New Jersey and holds Series 7, 63, and 65 licenses. Currently the Regional Vice President of Sales for Jemstep by Invesco, Steve has more than 20 years’ experience in the financial services industry.

Steve is an SUDC father. His son Jacob died in 2012 at the age of 26 months. Steve is an active member of the SUDC Foundation community. His contributions include: political advocacy for the SUDDEAA in 2014; bereavement support to other SUDC parents through the email support groups; hosting Jakey’s Cup, an annual golf outing; and participating in the Understanding SUDC Conference in May 2017.

Steve is also active in the San Francisco community, where he, his wife, and their two children donate their time and resources to several worthy and important causes, including SUDC, the Compass Family Shelter, the San Francisco Department of Animal Care and Control, and the Fred Hutchinson Cancer Research Center. We look forward to working with Steve and are confident his skills and experience will be an asset to our Board. We gratefully thank him for his willingness to serve.

Steve Myers
Private donations to the SUDC Foundation allow us to provide all services at no cost to death investigation professionals and families affected by the sudden, unexpected, and often unexplained death of a child. These services include:

**Family communication:** The SUDC Foundation staff can act as a liaison between the family and your office during the investigation, providing families with bereavement support and assistance navigating the investigation process with realistic expectations.

**DNA banking:** The SUDC Foundation advocates and supports DNA banking after the sudden death of a child to ensure opportunities for future genetic analyses. The Foundation provides logistical support for your office to obtain DNA banking for families. Financial support may also be available.

**Educational resources:** Through our website (sudc.org), newsletters, and social media updates, we provide you with up-to-date information about SUDC, including the latest publications on sudden death in children.

**Help for Families brochure:** This brochure can assist your office in communicating with families during the investigation of sudden pediatric deaths. The brochure explains the death investigation process, the professionals involved, and bereavement services. It is personalized to the needs of your specific office. Printing is available upon request.

**Support for families affected by the sudden, unexpected, or unexplained deaths of children older than 12 months:**
- Individualized case advocacy to help navigate the death investigation process
- Personalized support by licensed clinical social workers
- Private web-based peer support groups, specific to sudden unexpected child deaths and moderated by mental health specialists
- Peer support programs that match trained family volunteers with newly bereaved families
- Resources for siblings and grandparents
- Personalized memorial websites
- DNA banking
- SUDC research opportunities
- Access to the SUDC Foundation family directory
- Assistance with and resources for event planning and fundraising

**Contact us today:**
- info@sudc.org
- 800-620-SUDC
- www.sudc.org

**YOUR SUPPORT IN 2017 ENABLED:**
- Investments of $165,000 in the SUDC Registry and Research Collaborative (SUDCRRRC) to further the understanding of the cause(s) and ways to prevent sudden death in children.
- An award of nearly $100,000 to the National Association of Medical Examiners (NAME) to work collaboratively with the American Academy of Pediatrics (AAP) to investigate and establish national practice guidelines for investigations of sudden unexpected deaths in infants and young children.
- 1,242 hours of support services to help families through the grief process of losing a child.
- Advancement of public awareness of SUDC in 6 countries, 39 US States and 107 cities across the globe.

**Improved Access to Family Services**

The SUDC Foundation is committed to getting families the help they need as quickly as possible.

To enhance access to the comprehensive family services available at the Foundation, we recently conducted a stakeholder survey to get feedback from professionals, families, the medicolegal community, donors, and other SUDC supporters. Based on the survey results, we have reprogrammed and streamlined our online registration process, allowing families to connect with our services more quickly.

For more information, visit www.sudc.org.
Celebrating New Affiliate Launch: SUDC UK

The SUDC Foundation is pleased to announce the launch of SUDC UK, our affiliate in the United Kingdom. SUDC UK will enhance the Foundation’s efforts to support the needs of the SUDC community in the UK.

SUDC UK will spearhead an SUDC public awareness campaign and raise funds for expanded SUDC research initiatives. Through prior efforts, leadership of SUDC UK have raised over $228,000 (£184,500) to support SUDC and bereaved families. The SUDC Foundation will continue to provide bereavement support to SUDC families in the UK.

“We are so excited to announce the launch of SUDC UK,” said Laura Gould Crandall, Executive Director and Co-Founder of the SUDC Foundation. “The SUDC Foundation is proud of its history of being the only worldwide organization devoted to supporting those who have been devastated by SUDC. SUDC UK will help us expand our outreach efforts to support more UK families and advocate for research that will further our understanding of SUDC and ways to prevent it.”

“We, Nikki, Helen, and I are proud to announce the birth of SUDC UK, whose sole purpose is to promote awareness, advocate for more research, and build a connected and compassionate SUDC community,” said Camilla Gooden, Co-Founder of SUDC UK. “SUDC UK is launched in memory of all our children, and we hope we can make a difference by shining their light on SUDC. We are eternally thankful to the SUDC Foundation for supporting us on our journey to make this happen.”

SUDC UK celebrated its official launch on Saturday, April 21, 2018, at the Chessington World of Adventures Resort, supported by The Lullaby Trust. The event honored families whose toddler or child died suddenly and unexpectedly and featured a presentation on the work of SUDC UK.
The SUDC Registry and Research Collaborative (SUDCRRRC) was created in 2014 with the recognition that the medicolegal death investigation (MDI) community requires support to conduct comprehensive investigations into sudden child deaths that further research efforts. The SUDCRRRC brings together researchers from NYU Langone Health, Columbia University, and the Mayo Clinic, forensic pathologists, and crucial MDI partner offices.

Our goal is to better understand the characteristics, circumstances, medical histories, and pathologies of children ages 11 months through 18 years who have died suddenly and unexpectedly, and sometimes, without explanation. The SUDCRRRC:

- **Contacts the family** to explain the details of the study, and if interested, obtains their written informed consent to enroll.
- **Performs neuroimaging** and full neuropathology evaluation, with a full MR and neuropathology report to MDI office.
- **Performs genetic analysis** (whole exome sequencing) on the child who died, both biological parents, and certain family members. Provides genetic counseling upon completion of testing.
- **Reviews the child’s medical records**, family history, and death investigation to determine whether a cause of death can be identified and whether additional studies might be helpful. All data are entered in the largest SUDC registry to evaluate trends.
- **Ships kits** to MDI offices and covers all expenses incurred, including slide recuts and shipping costs and supplies.
- **Provides ongoing mental health support** to enrolled family members.

The SUDC Foundation and the SUDCRRRC are dedicated to supporting professionals and families affected by sudden unexpected deaths of children. By partnering with affected family members and the MDI community, we hope to understand these tragedies and assist in their prevention.

For more Information:  
www.sudc.org  
info@sudc.org  
800.620.SUDC (direct dial 973.239.4849)

Matching Gifts: An Easy Way to Support SUDC

Does your company offer a convenient way to support your favorite charity through a matching gift? Many companies, regardless of size, offer matching gift programs to employees as part of their corporate philanthropy initiatives.

Participating in a matching gift program can double or even triple your donation, providing a valuable source of additional funding for the SUDC Foundation. In fact, in 2017 the Foundation received over $9,000 in donations from corporate matching gifts.

If you would like to have your gift matched, speak with your company’s human resources department. You will likely be asked to complete an online submission form, which takes no more than 5 minutes. It is that simple!

Thank you for taking the time to ask your employer if a donation is eligible for a matching gift.

Shout Out to Recent Major Supporters!

Andrew’s Pins for a Purpose  
Brave the Shave  
Brooklyn Half Marathon  
Carnegie Coffee Company  
Dick’s Pittsburgh Marathon  
Drew’s Tunes  
Eating 4 Ezra  
Festival of Friends, Festa Das Amiga  
Jacob’s Joy  
Kaden’s Dance  
Levi’s Tupperware Fundraiser  
Light Up the Night for Norah  
Lula Roe for Kendall  
Maps for Maryann  
Mason James Foundation  
Moss Pieratt Foundation  
Orangetheory Fitness  
Pampered Chef for Logan  
Reuben’s Brews  
Team Vienna/Run with the Royals 5K  
Tee Off for Taylor  
The Max Challenge  
Thirty-one  
Vivienne’s Joy Foundation  
Yoga for Sean and Audra

And a sincere thank you to the passionate and dedicated efforts of the SUDC Foundation T-shirt and Facebook fundraising events.
The Facts on Complicated Grief

Grief is a normal and natural emotional reaction to loss. The loss of a child to a sudden and unexpected death provokes immense, overwhelming grief.

Complicated grief, however, is characterized as a prolonged experience of intense grief that occurs when the pathway to an adaptive grief response becomes obstructed, sometimes because of trauma. Specifically, complicated grief is “characterized by a period of overwhelming grief that persists for at least 6 months following the death of the loved one and is marked by profound yearning and powerful longing to be reconnected with the deceased.”1

Complicated grief can include:
• Maladaptive thoughts (eg, catastrophizing or second guessing)
• Dysfunctional behaviors (eg, extreme avoidance of reminders of their loved one)
• Inadequate emotion regulation (eg, disrupted routines and intense emotions)

These experiences can prolong the grieving process and make the grieving process more difficult to navigate.

What are some treatments for complicated grief?

Complicated grief treatment involves identifying and resolving grief complications. With the help of a therapist, the person with complicated grief can learn to manage emotions, talk about the future, strengthen their support systems, share their story of the death, and eventually, live with reminders and participate in remembering the person who died.

Therapy often involves cognitive behavioral techniques such as thought tracking and keeping a grief journal. About 70% of people who receive complicated grief treatment improve after 4 to 5 months, according to research from the Center for Complicated Grief.2

Please contact the SUDC Family Services staff at Lisa@sudc.org if you have questions about complicated grief or want more resources.

References:

Join Us at the Inaugural SUDC Family Retreat in Naples, Florida

Planned activities include a special “Mindfulness Meditation” workshop conducted by Matthew LaBosco. As a certified Conscious Transformation Trainer and Energy Practitioner, Matthew will educate participants on the neurological benefits of meditation following trauma, guide participants through a meditation session, and provide tools for a greater sense of well-being and stress reduction.

Additionally, renowned speaker, Nora McInerny, will connect with our families through her authentic and honest portrayal of common human experiences. Nora addresses challenging and uncomfortable topics like death, illness, mental health, and trauma with a light touch, using her disarming humor and wit to break down the barriers that often isolate people who are going through tough times.

The weekend’s schedule also offers much-needed leisure time. Families can relax and enjoy the onsite hotel amenities, as well as participate in a remembrance tribute on the beach, gather for group meals, play some golf, take a trip to the Naples Botanical Gardens, and much more.

“The retreat organized for SUDC families will be an extraordinary time to learn, share, and expand our capacity to grow in this journey that we have been pushed to achieve. Our kids, who have passed away, and our kids who are living deserve happy parents, and being together will help make us better people,” said Carolia Garcia.

“When I attended the SUDC Conference in New York, it had been one year since Gabriel left us and it was extremely difficult to open my heart, as I was just beginning the grieving process. Being together gives us courage. We are warrior parents and I am sure the SUDC family retreat will be a blessing for us all.”

If you would like to attend the SUDC Family Retreat or make a donation to help a family with travel and accommodation costs, please visit sudc.org/familyretreat/ or email us at info@sudc.org for more information.
Volunteer Spotlight: The Kratzer Family

Russ and Tiffany Kratzer’s son, Jacob Edwin, exuded such a contagious joy that his smile could make any day bright. On March 23, 2013, at only 27 months of age, Jacob went to bed after a fun day spent with his family and friends, and did not wake up the next day. Within a few months, Russ and Tiffany contacted the SUDC Program, now the SUDC Foundation, to receive personalized support. Today, the family actively volunteers with the Foundation.

“The SUDC Foundation was a huge support to us in so many ways in the months after we lost Jacob.” “We felt like we were going through a nightmare, and it was incredibly helpful to be connected with Laura and all the staff. They helped us with so many aspects of our life after such a sudden loss, and it was reassuring to be connected with other families who understood our experience.”

This past May, the Kratzer family hosted the 5th annual Jacob’s Joy 5K Run and Walk, created in honor of their precious son Jacob, to raise funds in support of the SUDC Foundation mission. Throughout the years, this event has raised more than $72,000 to promote awareness, advocate for research, and support those affected by SUDC.

“Jacob’s Joy is our way to honor the memory of our sweet boy, while raising money for the SUDC Foundation to hopefully help prevent this from happening to other families and to help support families like ours.”—Russ and Tiffany Kratzer

The SUDC Foundation is tremendously grateful to Russ and Tiffany, their family and friends, and all the dedicated volunteers who have participated over the past four years to help make this event a success. For more information on Jacob’s Joy, please visit, www.sudc.org/jacobsonjoy.