



NTSAD FAMILY CONNECTIONS

NTSAD

For Newly Bereaved Families | Month Twelve

Anniversary Reactions

BY LIVING WITH LOSS FOR SAN DIEGO HOSPICE SURVIVORS, ISS. 11

Perhaps one of the most common, yet disturbing, aspects of the grief process is the intensification of pain toward the end of the first year. This upsurge of grief is commonly known as an anniversary reaction because it seems to coincide with events and experiences of the previous year, as well as birthdays, wedding anniversaries, or other special occasions. You have probably noticed a sensitivity to certain dates, times, and seasons during the past several months. At this point, you may find yourself preoccupied with thoughts of your loved one's diagnosis and your shared experience of facing a terminal illness. Even if you never paid much attention to the actual dates at which certain critical events occurred, these memories may be affecting your emotional well-being. Many people fail to associate the sudden rush of fresh grief with the anniversary of the first sign of the illness, the diagnosis, the treatment, terminal prognosis, and death. Consequently, with this resurgence of grief comes anxiety and some confusion about the long-awaited resolution of one's grief.

For the most part, these anniversary reactions are a normal part of the [grieving] process. However, if you find yourself immobilized by these reactions for a prolonged period of time, you may wish to seek additional assistance. Many of the grieving people we have worked with find it helpful to come back to a support group for a while at this time.

As you know, we have come to view the grief process as a journey. While it may feel that you have regressed, the work which occurs at these times is significant and necessary to the further resolution of your grief. Just as the traveler takes periodic breaks during which he reviews his journey, anniversaries and other special occasions may give you pause for thought. As you approach the possibility of a new and different, yet meaningful life, you cannot help but look back at what once was, but can no longer be. It is during these times of suspended motion that you may be required to let go more fully. This letting go does not require that you forget your loved one, but rather, that you relinquish the pain of your grief and embrace the future more freely. In relinquishing the pain of your grief you have essentially lightened your pack, taking only those memories and experiences which will be necessary for your growth and enhance your capacity for happiness.

"Those we love never truly leave us, for there are things even death cannot touch." - Unknown

Resources:

Being an Advocate and Sharing Your Story

For information on ways you can become involved as a rare disease advocate from the local to national level, and help in learning how to effectively share your story, you can [view the advocacy session](#) from the 2021 Annual Family Conference.



Contact Us:

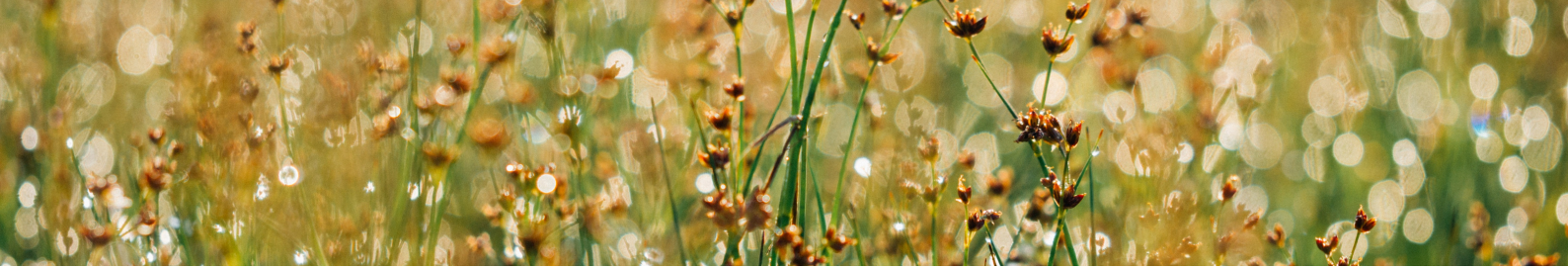


Diana Pagonis
Director of
Family Services
diana@ntsad.org
(617) 458-9013



Becky Benson
Family Services and
Conference Coordinator
becky@ntsad.org

Disclaimer: The content of this newsletter is intended for support purposes only and not intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your healthcare provider with any questions you may have regarding a medical condition.



Building A Legacy

BY NTSAD FAMILIES

As bereaved parents and families, we often talk about keeping our child's memory alive and seek ways to achieve this. We keep photos in our homes as reminders, talk about our children to our friends and families, celebrate them as often as possible, and honor them in the privacy of our hearts. If you are looking for more ideas on how to build a legacy for your child, look no further than the families of NTSAD. So many have created ways to honor their children and help others. Some volunteer with NTSAD. Others use kindness cards in memory of their child. There are book drives, golf outings, lemonade stands, motorcycle rides...the possibilities are endless. Below, two family members share their experiences for building a legacy and honoring their loved one.

Carly Gettleman, Brooke's Sister

There is a certain kind of emptiness that comes from having lost a sibling that you never met. My sister, Brooke, passed away from Tay-Sachs Disease before I was born. I felt a constant void growing up knowing that I should have a sister who was four years older than me. Since I didn't have any memories with Brooke to cherish, I wanted to do what I could to keep her memory alive. In an effort to do that, I have organized several fundraisers.

Beginning when I was in high school, I started organizing fundraisers in my sister's memory. It was a comfort to me that each person who came to the fundraiser saw a picture of or heard stories about Brooke, and learned about Tay-Sachs. I felt such a strong connection with my sister by honoring her legacy. Two years ago, during my junior year at the University of Florida, I coordinated a fundraiser at the Chipotle that is located across from campus. It was another chance for me to show her pictures, explain Tay-Sachs Disease and support NTSAD.

On February 13th of this year, Brooke would have turned 25. To honor my sister on what should have been a milestone birthday, I hosted a fundraiser in Brooke's memory. With my friends and other students who attended, I was able to celebrate Brooke's birthday by sharing with people what February 13th should have been. I have found fundraising to be a powerful way for me to connect with and honor my sister, Brooke.

Kevin, Mathew's Dad

We formed the Mathew Forbes Romer Foundation in 1998 in honor of our son, Mathew, who had Tay-Sachs Disease. We realized when Mathew was born in 1995, that South Florida lacked the services and expertise to screen at-risk groups, care for affected children, or work toward developing a cure for kids like Mathew with fatal genetic diseases. We wanted to change that. Matthew's strength inspired us to continue fighting in our mission to help other families, even after Mathew passed away in 2003.

It has been over 23 years since we started the MFRF, and we continue to honor Mathew's legacy with our programs. We have conducted over 25 education and screening events throughout the state of Florida. Our nursing education programs include 46 scholarships, patient and family care simulations, and presentations across multiple colleges of nursing campuses. Lastly, we are making tremendous progress toward treatments for Tay-Sachs and allied genetic diseases through the creation and expansion of the NTSAD Research Initiative, with more than 64 projects ranging from basic research to clinical trials.

We eagerly partner with organizations with common missions, love to share their stories, and recognize the many other children and affected families with whom we are forever connected. We continue our mission now in Mathew's memory, and continue to make a difference in his honor.

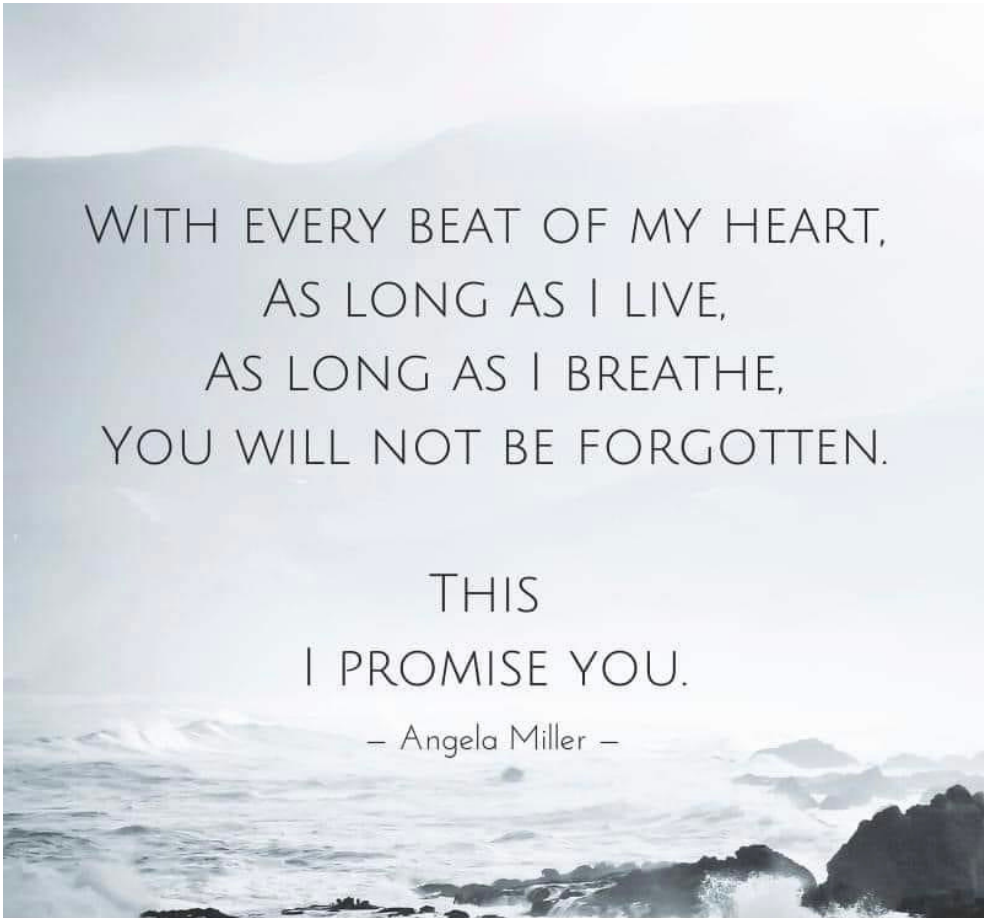
Moving Forward: Community and Connection

BY NTSAD FAMILY SERVICES

As we come to a close with our twelfth and final monthly Family Connection Newsletter, we at NTSAD want you to know that we understand this is not the end of your journey, and it's certainly not the end of our support for you. Many of us want a good deal of healing to happen after the first anniversary of our child's death, but don't be surprised if it doesn't change anything for you right away. As time goes on you may not even feel like your grief has lessened, but that it has changed. Some days will be better than others, but it will always be there.

The staff, board, and parent community members of NTSAD will always be here for you as you continue to navigate this path. From information and research, to advocacy and awareness, supporting families like yours is the center of everything we do. We hope you've found the articles and information in these newsletters to be both insightful and comforting. Just as importantly, we hope they helped reinforce that you are not alone.

We now have more ways to stay connected and support each other than ever before and our team looks forward to seeing you at the Annual Family Conference, Imagine and Believe, on our Facebook groups, or at one of the many events held throughout the year.



WITH EVERY BEAT OF MY HEART,
AS LONG AS I LIVE,
AS LONG AS I BREATHE,
YOU WILL NOT BE FORGOTTEN.

THIS
I PROMISE YOU.

— Angela Miller —