

# **UNITE Notes**

# Summer/Fall 2020 Vol. 39, no. 2

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P.O. Box 298, Oxford, PA 19363, www.unitegriefsupport.org, 484-758-0002

# Winter

(Editor's Note: As we approach the winter months and year-end holidays, I would like to share this beautiful message that was written in 1999 by our Executive Director, Janis Keyser. Janis lost her courageous battle with cancer in spring of 2004 but we will never forget all that she taught us.)

This time of year holds intrigue for me. It's not that I particularly like winter—actually I've learned to appreciate it as a concept, but not as a reality! But it is the winter solstice, the day of longest darkness that draws my attention. The idea of coming to the darkest point—the time of greatest despair that the light will be wiped out forever, that all hope will be lost—and finding instead that the light has begun to seep back in through the cracks, ever so slightly, but with great promise, gives me strength. Joseph Campbell, with his wisdom about mythology and life, wrote, "One thing that comes out in myths is that at the bottom of the abyss comes the voice of salvation. The black moment is the moment when the real message of transformation is going to come. At the darkest moment comes the light." This is the story of our year-end holidays—Hanukkah, Christmas, Kwanza. It is our story, too, in rising from the ashes of our grief.

UNITE's holiday wish to you is consistent with our mission all year through—for patience and strength through all the unknowns of our grief, for companionship through the pain, for love and acknowledgment of our children's lives, for healing that comes from facing the darkness as we hold onto hope for the light.

# Janis Keyser UNITE Notes, winter 1999





If you or your organization would like to sponsor an edition of *UNITE Notes*, please contact us at 484-758-0002 or via email at administrator@unitegriefsupport.org.

Thank you for your support.

# Professionally Speaking... by Denise M. Paul MA, CT, CPLC

# The Holiday Dilemma

Tis the season to be jolly....but for parents grieving the loss of their precious baby, they certainly feel anything but jolly! Department stores are adorned with festive holiday décor, and cheerful music rings in the season with songs that sometimes bring tears to the eyes of those who are mourning. Babies are seen sitting on Santa's lap in the mall, while your dreams of visits with Santa are shattered. The dilemma is that the rest of the world wants to experience joy and celebrations while you are grieving. Family and friends want everything back to normal, yet holidays "as usual" deny the loss and trivialize the life of your baby.

I'd like to offer some coping strategies as you approach the holidays:

- Be patient with yourself. Do what you can this season and let it be enough.
- Decide on a new way or a new place to spend the holidays.
- Be realistic and realize that hurting moments will come. Be ready for them and honor them, then let them go.
- Plan ahead. Prioritize what needs to be done, and decide what is really important.
- Be prepared for holiday well-wishers. Brace yourself and know that others do wish you well and that their greetings are not intended to be hurtful reminders.
- Redefine your expectations. Make a holiday checklist of things you would usually do regarding cards, decorations, shopping, and traditions. Be honest with what you expect to be able to do and don't feel guilty if you are not able to accomplish all that you had in previous years.
- Be flexible. Know that you are working through a challenging time and might have to make some changes.
- Take care of yourself physically. Eat right. Exercise. Rest.
- Screen all holiday activities and gatherings. Only attend the ones that you really want to. Have an escape plan ready. Give yourself permission to leave if you feel uncomfortable.
- Give yourself the gift of emotion. It's OK to cry, but it's also OK to laugh.
- Make shopping easier. Do what you feel you can handle. Shop on-line to avoid busy malls.
- Live through the hurt. Feel the pain that's how you will heal. Don't allow the pain or sadness to ruin the entire season. Joy can return to your heart.

Grieving is full-time work and holidays interrupt the grieving process. If you can incorporate some of these suggestions into your holiday planning, you may feel better prepared to cope with this difficult time of year.



# The International Wave of Light

The International **Wave of Light** is an annual event that takes place on Pregnancy and Infant Loss Awareness Day, October 15. Candles are lit around the world in all time zones at 7:00pm and they remain lit for exactly one hour.... Parents, family, and friends are encouraged to **light** candles in memory of their children. Here are pictures of our UNITE members honoring their children.















# Infant Memorial Service at Holy Redeemer Hospital

A memorial service is an ideal place to acknowledge that while death may have taken away our babies' physical presence, they will continue to live on in our memories forever. Holy Redeemer Hospital held their virtual Infant Memorial Service on November 7<sup>th</sup> of this year. We would love to hear about other memorial services that UNITE Groups hold throughout the year.

Holy Redeemer Hospital's Memorial Service can be viewed at <a href="https://www.holyredeemer.com/memorialservices">www.holyredeemer.com/memorialservices</a>







This Wall Hanging Contains the Names of the Babies Who Left This World Too Soon

# Grieving the Death of a Child



When my child died, at first I was in shock. I couldn't believe it happened and, months later, I still would have that feeling at times---that is was all a bad dream. But in the beginning it didn't seem to register. And when it did, my emotions would come to the fore. I simply could not or would not accept it. Children are not supposed to die before their parents.

But during the second month, it really began to sink in, and the numbness wore off, and I began experiencing long periods of overwhelming anguish. I didn't have the energy to deal with everyday challenges or responsibilities, like I had previously. I'd snap at my other children or my husband\d, even though I came to realize that they were hurting in their own way, not always obvious to me. In my helplessness, I wanted a way to get a sense of control so I would feel less helpless. If I could only decide who was responsible for this, it would help. Was it God, the doctors, or even something I didn't do to prevent this? And yes, I felt guilty about a lot of things, even though I knew in a way I did my best at the time.

When I began to have some good periods, however brief, I would sometimes feel guilty. Like I shouldn't laugh out of loyalty to my deceased child. And if others saw this, they would think I was doing better, and was on an upward course toward resolving my grief. What a dumb idea! As if anyone can fully resolve the death of a child. And my fears really started to magnify. I tended to be a bit protective, even before my child died, but now I would have these waves of panic that something was about to happen to one of my other children or my husband. And the emotional turmoil during these months included difficulty making decisions, such as to how to handle my life and my relationships with others. Should I go to my sister-in-law's shower or any other presumably happy social occasion? Suppose I break down and dampen everyone else's good time? Suppose I encounter one of those insensitive things that people say, but which don't help: "Time heals all wounds...Now you have an angel in Heaven...I know how you feel."

With the passage of time, I came to realize that I was changing in dramatic ways. Material things mattered less. I began to realize that we don't have control over

many things I previously took for granted we do. I started to be more empathic regarding others. Ironically, some of the people I thought I had so much in common with before, no longer seemed to be my closest sources of support. Their concerns seemed trivial, or they seemed to avoid me, or would appear to grow impatient that my grieving wasn't ending. Eventually, I was able to confront and re-establish a new relationship with some, but not others.

Since nothing of this magnitude had ever happened to me before, I was unfamiliar with what I was going through emotionally. Was I going crazy? Why was it taking so long to get back to my old self? And how come I kept slipping back to such intense periods of grieving after so many months? And so much could set me back – a TV commercial, a special date or anniversary, or dreams I had about my child's future which would come into my thoughts "out of nowhere".

What helped most was when I could talk about my child to someone, the meaning of my child's life to me, share my feelings, cry, express my anger, and get a caring, listening response. I knew no one could fully understand my pain, but it helped if someone gave me a chance to tell about it.

With the passage of time, I started to heal. The intervals of intense emotional pain came less frequent, didn't last as long, and I was more assured that is would help if I didn't fight it. I started doing things in honor of my child – attending a memorial service, sending a donation in her name, etc. Now that it is several years later, I believe I'm a different person, in many ways, than I was before this happened. I've put my energy into making the best of my life with my family. But at special times, and others, I still can re-experience a sense of grief and loss, echoing what I felt in the months right after she died. And I'm sure I'll carry my child, and her loss, in my heart to my final days.

This passage was written by John Murray, Ph.D., Psychologist. John has summarized so beautifully, the many thoughts and feelings experienced by grieving parents.

# Thank You!

UNITE, Inc. would like to extend our heartfelt thanks to Cathy Plaisted who volunteered as the UNITE Recording Secretary. Cathy recently stepped down from her positions after being a part of the UNITE family for many years. All of the UNITE volunteers give their time to help UNITE continue the mission to be there for grieving families today and in the future. We are forever grateful to them all.

Thank you from the UNITE Board and Facilitators



# Amazon Smiles

Everyone,

With the Holidays just around the corner....

UNITE could really use your help this year.

When ordering online from Amazon, please choose UNITE, Inc. as the organization you would like to support. UNITE will get a percentage back from what each person spends on Amazon Smiles. You have to use the link below.

Wrap up your holiday shopping at smile.amazon.com/ch/23-2362403 and AmazonSmile donates to Unite Inc.

Copy this URL into your browser --- www.smile.amazon.com/ch/23-2362403 Then Shop....it's that easy!

Please also share with family and friends!

Thank you, Barbara Bond-Moury UNITE Board Chair

# The Black Sweater

Many years ago my mother and I signed up for ceramics together. If you've ever done this type of craft, you know it can be a messy project, so we used to wear our oldest t-shirts to class. Each week we'd show up and there was a woman who came dressed in a black sweater. She regularly made comments about how awful she looked when leaving, so finally we asked – why would you wear a black sweater, knowing you'd walk out so full of dirt and dust?

She explained that she was in mourning and in her family it is a sign of respect to the person who died to wear black for an entire year following the death. At the time my Mom and I were amazed! Wear black for an entire YEAR!?

When I lost my baby girl many years later I longed for something, anything, some universal recognized symbol, which would identify me to the world as a fragile grieving Mom. But there was nothing other than my sullen face to reflect my broken heart and my empty arms. In my mind it was because society is just so afraid of death in general and a child's death in particular, that we cannot entertain the idea of an outward sign of such a loss.

My beloved Dad passed away ten days ago and again I am plunged into the depths of grief. Once again, my relationship with him was like no one else's, and there is no outward sign to anyone of my broken heart. While I entertained the idea of wearing black for a year, I know that is not something that my Dad would support. Although at the end of each day I am overwhelmed by my grief and the tears flow – keeping the 'stiff upper lip' for my co-worker's and client is not easy - I know he was proud of me, and loved me so much. We spent his last few days together constantly, telling one another how much we loved one another. I am still so sad for my loss, although it is what I prayed for – an end to his suffering.

I am older and wiser, but some things still remain the same. Grief is a rugged journey and even when we think we are prepared and have traveled the road before, it can surprise us.

If you find yourself on the journey for the first time (or for the second or third), remember to be kind to yourself and to your whole body and soul. In the words of our wise and wonderful late friend Janis Keyser, all will be well.

In loving memory of Serena, still born 8/29/91 and her Pop-Pop, finally at rest 2/19/12

Linda R. Visconti



# The Meaning of the Leaf and the Teardrop

When I was in the hospital, they gave me a card with a poem and the meaning of the leaf and the teardrop. I wanted to share it for all of you have experienced losses as well, in hopes that meaning brings you a little comfort.



A growing leaf, green in color, has fallen prematurely.

It has separated from the tree of life and landed in a pool of water, of many tears. It is a dark moment. A human tear lingers on the freshly fallen leaf... before it turns brown.

Fallen.

Drifting aimlessly on a sea of grief and pain the leaf cradles a teardrop.

Offers refuge.

Embodies hope.

Just as winter awakens to spring, our deepest sorrow harbors the seed of hope renewed.

Hope renewed.

Author Unknown

# Fathers and Grief



When is it my turn to cry? I'm not sure society or my upbringing will allow me a time to really cry, unafraid of the reaction and repercussion that might follow. I must be strong, I must support my wife, because I am a man. I must be the cornerstone of our family because society says so, my family says so, and, until I can reverse my learned nature, I say so" (A father in DeFrain, J., L. Ernst, D. Jakub, and J. Taylor, J. 1991, 112).

Although both mothers and fathers grieve deeply when such a tragedy occurs, they grieve differently. Fathers are expected to be strong for their partners, to be the "rock" in the family. All too often fathers are considered to be the ones who should attend to the practical but not the emotional aspects surrounding the death; they are expected to be the ones who should not let emotions show or tears fall outwardly, the ones who will not and should not fall apart. Men are often asked how their wives are doing, but not asked how they are doing.

Such expectations place an unmanageable burden on men and deprive them of their rightful and urgent need to grieve. This need will surface eventually if it is not expressed. It is not unusual for grieving fathers to feel overwhelmed, ignored, isolated, and abandoned, but many say that such strong emotions are very difficult to contain after their child's death.

A father's grief needs to be verbalized and understood by his partner, other family

members, professionals, coworkers and friends, and by anyone who will listen. Fathers repeatedly say that for their own peace of mind, they (and those who care about them) need to move away from this mind set and allow themselves to grieve as they need to.

Lovingly Lifted from The Death of a Child, The Grief of the Parents: A Lifetime Journey (U.S. Department of Health and Human Services, Health Resources and Services Administration)

If you simply can't understand why someone is grieving so much, for so long, then consider yourself fortunate that you do not understand.

Joanne Cacciatore

# Eric and Joshua's Plant

The birth of a child is supposed to be a happy time. The birth of twins even a happier time. Unfortunately, Eric and Joshua's births were far from happy and very scary. They were born way too early and each only weighed 1.5 pounds. They lived for only three weeks and they never left the NICU.

When they were born, family and friends didn't know how to act or what to say. Most just avoided us and some offered condolences. Three days after they were born, my sister's inlaws sent us a gift basket with live plant in it and a card saying congratulations. When it arrived I was very angry. I remember thinking why would they send us this plant to congratulate us on becoming first time parents when our babies' lives were so precarious. What were they thinking? I put it aside and didn't want to look at it.

After a few days, I went through the basket and found a few little baby toys that I put into their incubators. I still have those toys in the memory box I put together for them. I also still have the plant that they gave us. It's 22 years old and has gotten quite big over the years. I was able to break it apart and make several plants out it. Every time I look at the plant I think of my babies. Not that I need a plant to remind me of them since I think of them every day. But, I feel like this plant has a connection to my babies because it was one of the few things I have where someone said to us, "I know this is a scary time but it's also a happy time. You are parents to two little baby boys. Make the most of the time you have with your boys, however short it may be." I will cherish those three weeks I had with Eric and Joshua. I will never forget my time with them.

I don't really know where I wanted to go with this story. I just wanted to share Eric and Joshua's plant with you.

> In Honor of Eric and Joshua Born Too Early...Gone Too Soon Theresa Fisher



Be Strong now because things will get better.

It might be stormy now, but it can't rain forever.

# Summer/Fall 2020 Donations

We Are So Grateful for Donations Given Throughout the Year

## **Donations**

Andrew Langsam
Shannon Ryan
Christina Christie
David & Ann Dickey in Memory of Travis &
Amy's baby and Kaia Dickey
Cindi Callahan
Mariarose Maria

## Walk to Remember Donations 2020

The Rowland Company Andrea & William Devenney

## **Butterfly Memorial Wall**

Barry McClure in memory of Kali Burgess Julie Jacobs in memory of Aubrey Rae Shapiro

# Walk to Remember 2020 – Wave of Light

Annie Chan in memory of Kaia Dickey Andrea & William Devenney in memory of Anthony Manus Devenney Tami Leather in memory of Marissa Catherine Leather Keturah Fisher in memory of Everson James Fisher

### Grants

The Merck Foundation Your Cause Foundation United Way Amazon Smiles Johnson & Johnson

#### **In-Kind Donation**

Denise Paul and Sandy Smith – Donation of their time for the UNITE Facilitator Training performed in October 2020

#### UNITE's Services Include:

- Support Group meetings in Pennsylvania and New Jersey.
- Hospital In-service Programs and community education.
- Conferences for bereaved parents, professionals and the community.
- Literature and newsletter.
- UNITE group development assistance and training programs for group facilitators and support counselors.

Without Your Most Generous Donations, UNITE Would Not Be Able To Continue These Services





# Mailing Address and Phone Number

Please note our new mailing address: P.O. Box 298, Oxford, PA 19363

## Phone Number

Please note our new phone number: 484-758-0002

## Safe Arrivals

We would love to hear about your safe arrival so we all can celebrate in your joy. So we can put it in the newsletter, please send information on your new bundle of joy to <a href="mailto:administrator@unitegriefsupport.org">administrator@unitegriefsupport.org</a>

# **Home Page Info**

# www.unitegriefsupport.org

Virtual Butterflies: The donation cost for placing one of these virtual items on the page is \$25 and will be in memory of your baby. You may donate through PayPal by clicking on the Buy Now icon. Note: On the PayPal page, where it states, "Instructions to the Merchant," type in your baby's name, etc.

# **Newsletter Submissions**

Please send your original poetry, short stories, articles, and letters to *UNITE Notes*. The beautiful writings that we receive from UNITE's bereaved parents are what make our newsletter so special. If you have written poems, articles, etc. that you would like to share with other parents, please send them soon. Note that the newsletter is now being uploaded to the UNITE website which allows all who are

searching for comfort and support due to the loss of their child(ren) to see your written story.

## **Acknowledgments**

If anyone has not received an acknowledgment for their donation, please contact the administrator@unitegriefsupport.org, or call the UNITE line at 484-758-0002. Please leave your name, phone number, and the best time to return your call.

## **AmazonSmile Foundation**

The Foundation runs a program in which Amazon donates 0.5% of the purchase price of eligible products to charitable organizations. To shop go to smile.amazon.com from your web browser on your computer or mobile device and choose UNITE, Inc. Products will be marked "Eligible for AmazonSmile donation" on their product detail pages. You may also go to our web page: www.unitegriefsupport.org and click on the icon/banner, which will bring you to smile.amazon.com. You should bookmark this page so that you go directly to your Amazon Account and start shopping. Purchase of digital content, such as Kindle e-books or MP3's, is not included.

# **Fundraisers Wanted**

We are looking for some fresh ideas in fund raising! Do you have an idea to share? We'd love to hear about it. Please contact UNITE at administrator@unitegriefsupport.org.

# **Support Groups**

# UNITE in-person support group meetings are suspended until further notice Please Call 484-758-0002 if you would like to attend a UNITE Virtual Support Group

For information about the group nearest you, please contact UNITE, Inc. at 484-758-0002 (leave a message), write to UNITE Inc. at P.O. Box 298, Oxford, PA 19363, or email <a href="mailto:administrator@unitegriefsupport.org">administrator@unitegriefsupport.org</a>. New members <a href="mailto:must">must</a> contact the group coordinator before attending their first meeting. UNITE, Inc. does not discriminate on the basis of gender, age, marital status, religious belief, race, sexual orientation or economic status.

## Pennsylvania

#### **UNITE, Delaware County Memorial Hospital**

Drexel Hill, PA
Meets 2<sup>nd</sup> Wednesday, 7:00 PM-8:30 PM *Facilitators*:
Debbie Rafferty
Michelle DePrince
484-758-0002

#### **UNITE, Holy Redeemer Hospital**

Huntingdon Valley, PA
Meets 3<sup>rd</sup> Thursday, 7:00 PM - 9:00 PM *Facilitators:*Denise Paul
Liz Steward
484-758-0002

#### **UNITE, Jennersville Regional Hospital**

West Grove, PA Meets 1<sup>st</sup> Tuesday, 7:30 PM - 9:00 PM <u>Facilitator:</u> Karen Powers 484-758-0002

#### **UNITE**, Lankenau Hospital

Wynnewood, PA Meets 3<sup>rd</sup> Tuesday, 7:30 PM - 9:00 PM <u>Facilitator</u>: Paris Margaritis 484-758-0002

## **UNITE, Riddle Memorial Hospital**

Media, PA Meets 1<sup>st</sup> Thursday, 7:00 PM - 8:30 PM *Facilitators:* Regina Fazio Sheila McCabe 484-758-0002

#### **UNITE**, Pennsylvania Hospital

Philadelphia, PA Meets 1<sup>st</sup> Tuesday, 6:30 PM - 8:00 PM *Facilitators*: Michelle Ferrant Kelly Colby 484-758-0002

#### UNITE, University of Pennsylvania Medical Center

Meets 3<sup>rd</sup> Tuesday, 7:00 PM - 8:30 PM *Facilitators*: Kelly Zapata Vicki Kroesche

#### UNITE, Paoli

484-758-0002

Paoli Pointe Medical Center, next to hospital Meets 2<sup>nd</sup> Monday, 7:00 PM - 8:30 PM *Facilitators*:
Sue McAndrew
Gerri Donaher
484-758-0002

## **New Jersey**

#### **UNITE, Penn Medicine Princeton Health**

Meets 1<sup>st</sup> Wednesday, 7:00 PM - 9:00 PM Contact: Debbie Miller, RN *Facilitator*: Bernadette Flynn-Kelton BSN, RN 484-758-0002

#### **UNITE, Virtua at Voorhees**

Barry D. Brown Health Education Center Meets 1<sup>st</sup> and 3<sup>rd</sup> Monday 7:00 PM - 9:00 PM <u>Facilitator:</u> Ann Coyle, RN 484-758-0002

# Subsequent Pregnancy Groups

#### **UNITE**, Virtua at Voorhees

Barry D. Brown Health Education Center Meets 2nd Tuesday, 7:00 - 8:30 PM <u>Facilitator:</u> Ann Coyle, RN 484-758-0002

#### **UNITE, Virtual Support Group**

Virtually on Zoom by invitation
Meets 1<sup>st</sup> Monday, 6:30 PM - 8:00 PM *Facilitator:*Denise Paul
484-758-0002

UNITE Notes Staff
Editor: Theresa Fisher

Administrator: Barbara Bond-Moury

**Submissions:** We welcome your original poetry and articles. Your contributions are important to UNITE's work of reaching out to bereaved parents. We reserve the right to edit and select from submissions. Please send all submissions to:

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