

# Death Goes Digital:

Making Social Media Work for Grief Support

March 7, 2018

Presented by Michelle A. Post, MA, LMFT

Facebook/Google+: Michelle Post LMFT

Twitter/Instagram: 1HeartHealerLA

[www.Michelle-Post.com](http://www.Michelle-Post.com)





Where does this title come from?



2012:

Mourning becomes electric: Tech changes the way we grieve

<http://www.usatoday.com/money/industries/technology/story/2012-05-07/digital-mourning/55268806/1?sf4452458=1>

Michelle A Post, MA, LMFT  
[www.Michelle-Post.com](http://www.Michelle-Post.com)



**Chat  
with us!**

**Hello!**



# Intro to OneLegacy:

- **One of 4 Californian OPOs**
- **Organ, Eye and Tissue donation organization**
- **Serve 21 million people**
- **Cover 7 Counties**
- **LARGEST in the world**



# OneLegacy's Mission Statement

“OneLegacy saves and heals lives through organ, eye and tissue donation,  
comforts the families we serve,  
and inspires our communities to  
Donate Life.”



saving lives through organ, eye & tissue donation



# Introduction to OneLegacy



- Approximately 4000 new donors served/year
- 2 to 10 family members per family
  - up to 40,000 new donor family members per year
- Follow each family for 3 years min

## Introduction to OneLegacy



Donor families in:

Southern California Community - DIVERSE!

Every US state plus Puerto Rico (e.g., Hawaii, Virginia, NY, Alaska, DC, Texas, Iowa, Michigan)

Some international (Haiti, Bahamas, Philippines, South America, Europe, Japan, etc.)

# OneLegacy On- Line Grief Group History

Things do not happen in a vacuum!

- MP hired March 2007
- Job Description = online grief support group?!?!?
- Former Director  
heard Robin Cowherd  
& Healingthespirit.org



*Soul Searching*  
BY MICHAELLO



**CHANGE**

**AHEAD**

# OneLegacy Facebook History



MP took DFSC course from Josie Flores of Life Alliance (LAORA) March, 2011  
MP Began to research FB & OPOs

MP took Website Design and Social Media Course from [www.comfortzonecamp.org](http://www.comfortzonecamp.org) at NAGC's Symposium-  
[www.childrengrieve.org](http://www.childrengrieve.org)) June, 24, 2010

+ Create A Page

Now

May

2012

2011

**SOME COMFORT = SUCCESS?**

Life Alliance (LAORA) Fan Page  
Joined Facebook  
July 8, 2009

RoseParade Float Fan Page October

November  
October  
September

**TOO MUCH COMFORT = PARALYSIS!**

March 6, 2009  
Transplant Buddies Fan Page  
Feb 6, 2009

Founded



**Chat  
with us!**

**Hello!**



# Potential Generational Challenges:



Michelle Post LMFT

9 hrs · 🌐

#Selfcare includes laughter... these texts between parents and their kids made me laugh out loud. Take 2 minutes for #stressmanagement and #laugh



## BRIGHT SIDE

17 hilarious texts between parents and their kids



# Age of users



## ADULTS VS TEENS HOW THEY USE SOCIAL MEDIA

The Pew Research Center recently released a report on how adults use social media, which made us wonder how teens and adults stack up with social media use. Teenagers today grew up in a digital world, so it is no surprise that they are preoccupied with all things online and technology. Surprisingly, though, when it comes to early adoption of social media, adults seem to have teens beat, if only slightly.

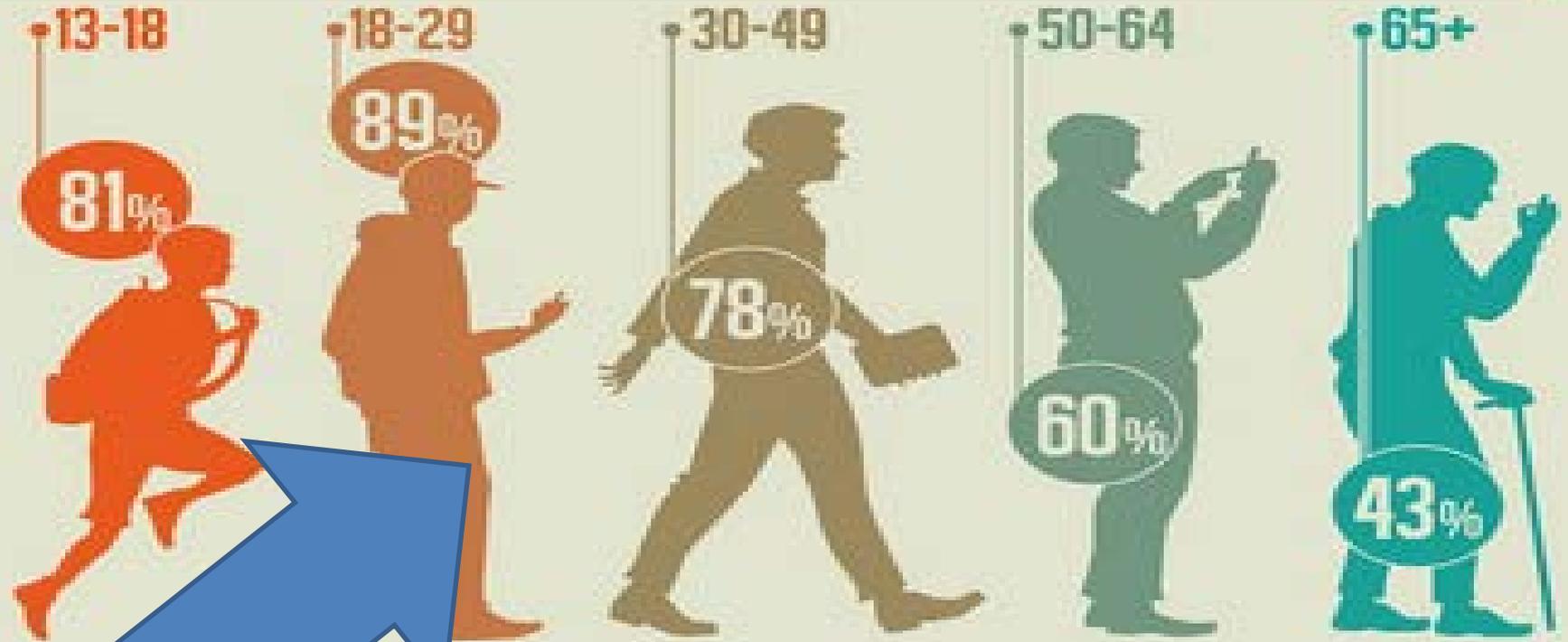


### OVERALL SOCIAL MEDIA USAGE



# Age of users

## AGE BREAKDOWN (OF SOCIAL MEDIA USERS)



Source: Pew Research Center studies from August 2013, May 2013 and February 2013.



# Teens and Social Media



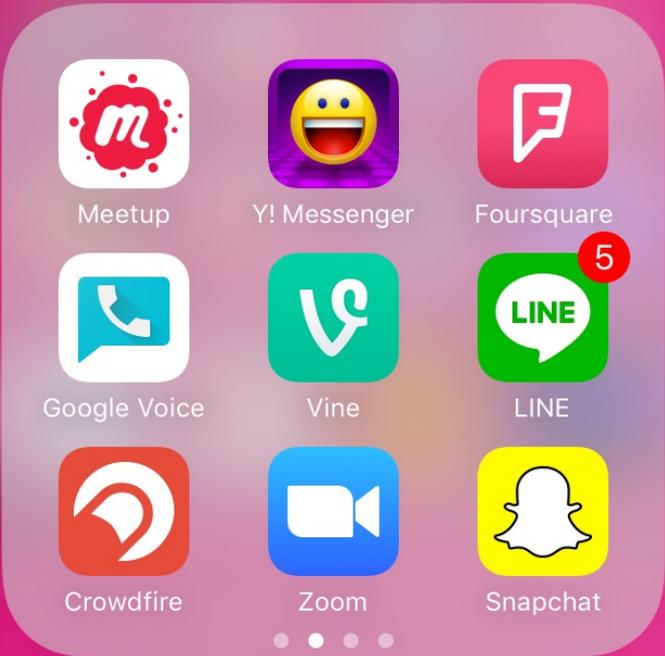
- 97% of teens report going online daily
- Nearly 75% of teens have access to a smart phone
- The top 3 social media sites used by teens are Facebook, Instagram, and SnapChat
- A typical teen sends 30 texts per day



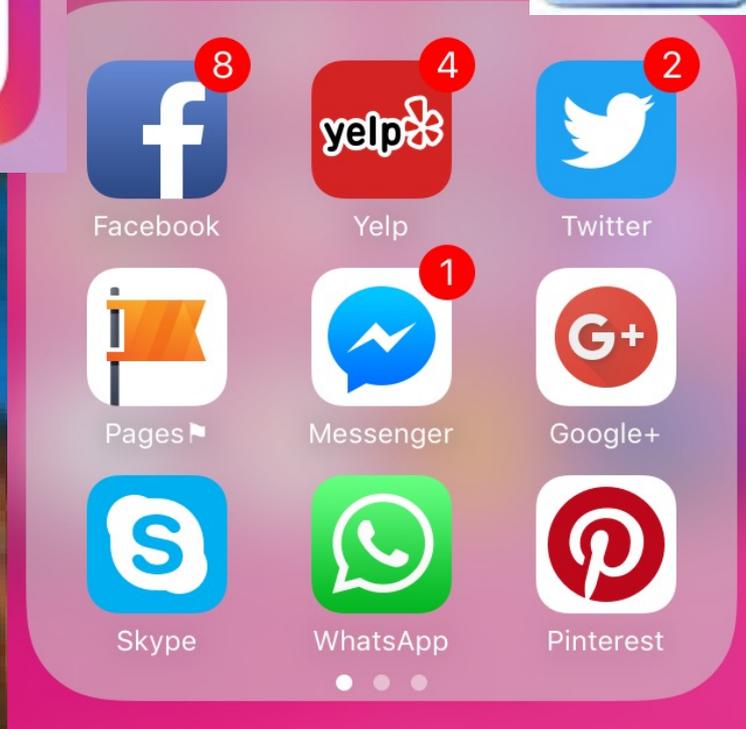
# National & International



Social



Social



## Why did we go with Facebook?

### KEY LEARNING POINTS (2010):

- Key to long term sustainability is being able to edit the content.
- People already on it; check regularly (500 Mil+)
- Easy to share photos, videos, events, new info
- 2-way+ convo w your database
- Note: person who creates your fan-page, owns your page, cannot be removed, admins can be changed.





# Benefits of an online grief support group

- **Convenient Support easily accessible**
  - **Can be accessed at any time**
  - **Those who don't share can still feel supported**
- **Reaches more people than traditional support groups >> Not dependent on transport**



saving lives through organ, eye & tissue donation



# Online Resource since 2011



Facebook Group for Donor Families  
“OneLegacy Donor Families”  
**secret group**  
Donor Families post 24x7



saving lives through organ, eye & tissue donation





# Stats: Where are we now?



## Michelle Post, LMFT & OneLegacy/OneLegacyNews



Facebook Group: 516 People (E & S)

Facebook Fan Page (OL): 3K to 1.5K followers

Facebook Fan Page (MP): 886 followers

MP's "Psychotherapist Network Group": 1104



Twitter (MP): 2617 followers



Instagram (MP): 528 followers



(MP): 1739 connections



# Why Turn to Social Media

## Perceived Safe Space:

- Publically announce grief and event
- Ease of Sharing

## Publically Memorialize the Death

- Space able to remember, honor or celebrate
- Facebook page of deceased digitally preserved

## Support and Validation

- Millennials are “Digital Natives”
- Younger generation mourns where their peers are

# Advantages

- 
- 24/7 access to peers
  - Online memorials bring those grieving together
  - Less calls/texts to the bereaved while still recognizing the loss

# Disadvantages

- 
- Potential for deceased to become “frozen in time”
  - Memories pop up on feed when unexpected
  - Can learn about the death online with no support
  - Potentially inaccurate information
  - Expose to cruel or negative feedback due to anonymity factor
  - “Overshare” info



# Digital Voice



Hilary Czarda  
Donate Life America



# Digital Voice



- Storytelling
- Tools
- Tactics



# Storytelling

- Words
- Visuals
- Strategy



# Storytelling



- The 1<sup>st</sup> story you need to tell, is YOURS.
  - What story does your organization want to tell?
  - How do you want to tell it?
  - Who are you talking to?

# Storytelling

- To know your story and how to tell it, you need to know:

What is your social media personality?



Hilary Czarda  
Donate Life America



# Storytelling



## Personality

- Who you are on your social media channels should match your organization's culture and mission/values in life.
  - a feisty advocacy organization? Tweets/posts should be feisty & fierce.
  - Innovative medical organization? Be innovative and cool.
  - Work with grief/Hospice families? Be kind and compassionate.

Hilary Czarda

Donate Life America



# Storytelling



Know who you are.

Think about why you are on social media and who you are talking to.

- Who are your **3** audiences
- What are your **3** reasons to exist on social

Hilary Czarda

Donate Life America



# Take 3 Minutes



- Who are your **3** audiences
- What are your **3** reasons to exist on social





PINTEREST

SOCIAL SITE THAT IS ALL ABOUT **DISCOVERY**

LARGE OPPORTUNITIES



USERS ARE:

**20% MALE**

**80% FEMALE**



**150 MILLION ACTIVE USERS**



TWITTER

MICRO BLOGGING SOCIAL SITE THAT LIMITS EACH POST TO **140 CHARACTERS**

MORE OVER 100 MILLION USERS



**6,000 TWEETS ON AVERAGE HAPPEN EVERY SECOND**



**328 MILLION ACTIVE USERS**



FACEBOOK

MOBILE IS FACEBOOK'S **CASH COW**



**1.15 BILLION DAILY ACTIVE MOBILE USERS**

**AGE 25 TO 34 AT 29.7% OF USERS IS THE MOST COMMON AGE DEMOGRAPHIC**



**1.5 BILLION LINKS MINUTES**



**2.01 BILLION MONTHLY ACTIVE USERS**



INSTAGRAM

SOCIAL SHARING APP ALL AROUND **PICTURES AND NOW 60 SECOND VIDEOS**

MANY BRANDS ARE PARTICIPATING THROUGH THE USE OF **# HASHTAGS**

AND POSTING

**PICTURES CONSUMERS CAN RELATE TO**

MOST FOLLOWED BRAND IS

**NATIONAL GEOGRAPHIC**



**700 MILLION ACTIVE USERS**



SNAPCHAT

APP FOR SENDING **VIDEOS AND PICTURES** THAT DISAPPEAR AFTER BEING VIEWED

**10+ BILLION VIDEO VIEWS DAILY**

ROUGHLY **70% OF** **USERS ARE FEMALE**

**MOST USED PLATFORM AMONG 12 - 24 YEAR OLDS**



**300+ MILLION ACTIVE USERS**



LINKEDIN

**BUSINESS ORIENTED** SOCIAL NETWORKING SITE

BRANDS THAT ARE PARTICIPATING **ARE CORPORATE BRANDS** GIVING POTENTIAL AND CURRENT ASSOCIATES **A PLACE TO NETWORK & CONNECT**



**70% OF USERS ARE OUTSIDE THE U.S.**



**106 MILLION MONTHLY ACTIVE USERS**



# Tools



- Facebook
- Twitter
- Instagram
- YouTube
- LinkedIn
- Pinterest





# Tools

*start here*

## Facebook

- 80% of US is on Facebook
- Age 25-34 is the most common demographic (30%)
- 5 new profiles are created every second
- One in 5 web page views in the US occurs on Facebook
  
- Business pages, easy to manage and measure
- BIG new focus: Groups



Hilary Czarda

Donate Life America



# Tools

## Twitter



- 500 million tweets every day
- 65 million users in the US
- 1/3 of US teens, 42% 15-17 year olds\*\*
- 30% 18-50 year olds; 13% 50-64
- Mobile!
- 140 (280) character limit
  
- Quick response & engagement, RT
- Build on trending hashtags (e.g., #MondayMotivation, #WednesdayWisdom)

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Donate Life America



# Tools

## Instagram



- 700 million users; 77.6M in US
- In US, 31% women, 24% men
- 32% of all internet users are on Instagram
- 59% of internet users 18-29; 33% 30-49
- 17% teens say it is most important site (growing)
- **Posts with at least one hashtag average 12.6% more engagement. #cool**
- VIDEO

Hilary Czarda

Donate Life America



# Tools

## LinkedIn

- Professional networking
- SME/Innovation
- Leadership



# FaceTime





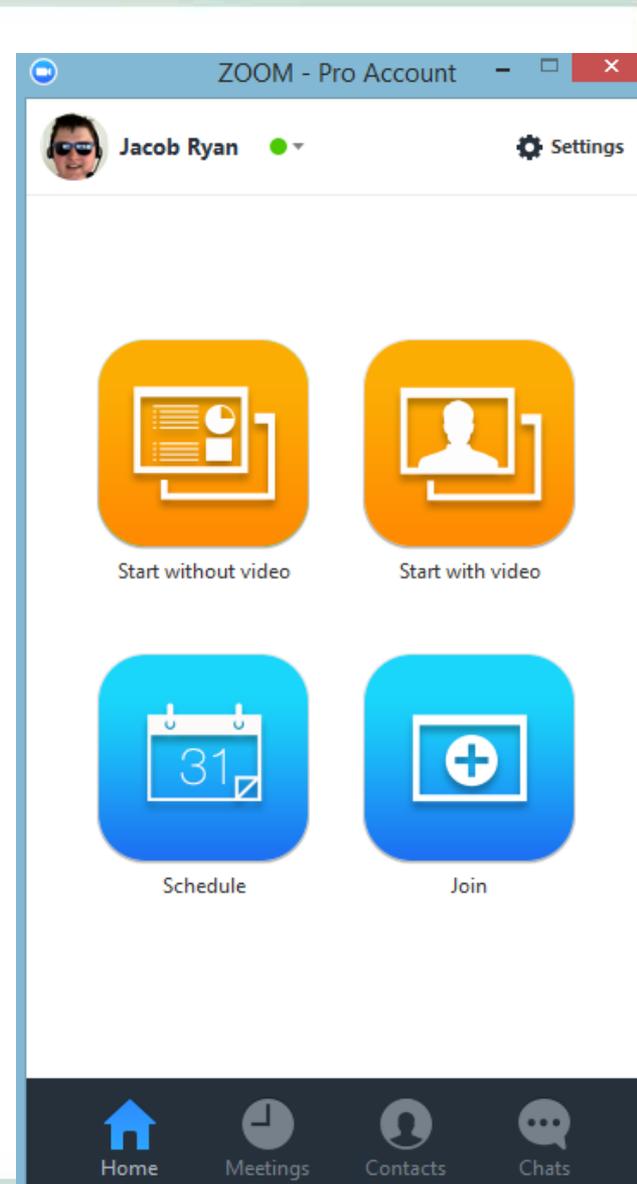
# Zoom

<https://support.zoom.us/hc/en-us/articles/201362033-Getting-Started-on-PC-and-Mac>



You can:

- Group or private chat ([learn more](#))
- Record your meeting ([learn more](#))
- Manage participants ([learn More](#))
- Mute and unmute your audio
- Select audio options ([learn more](#))
- Stop and start your video



# GoToMeeting

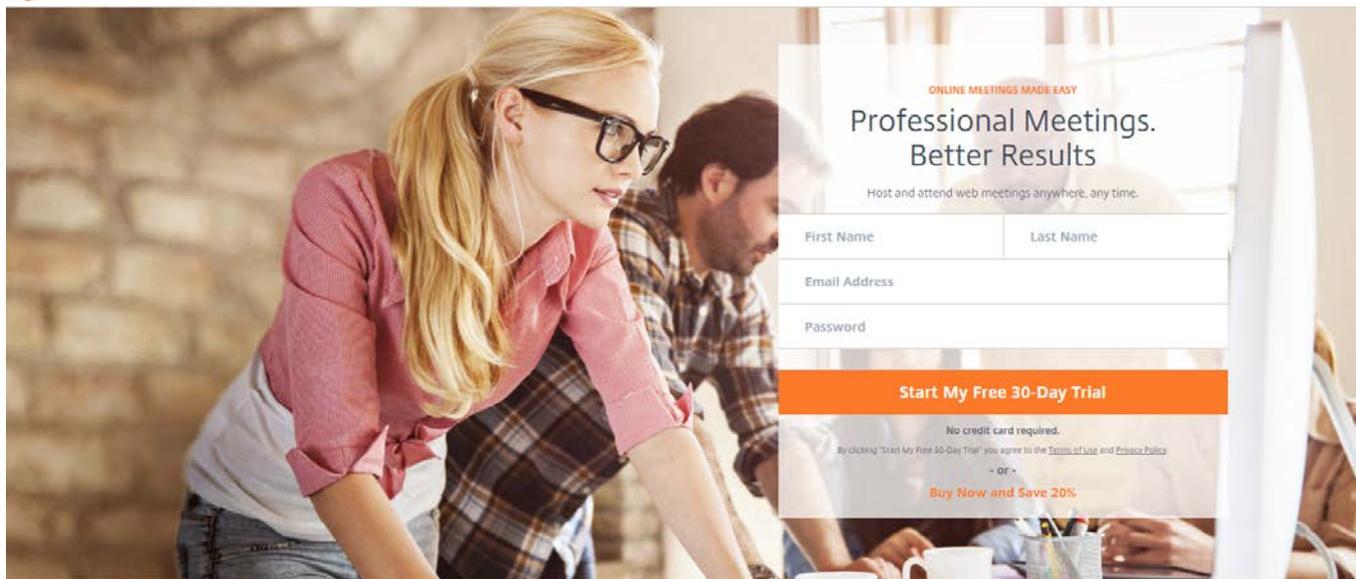
National Hospice and Palliative Care  
Organization



www.gotomeeting.com



 GoToMeeting



WHY GOTOMEETING

Connect with anyone, anywhere. On any device.

You can:

- Group or private chat
- Record your meeting
- Manage participants
- Mute and unmute your audio
- Select audio options
- Stop and start your video



# Tactics



Make a PLAN: build a content CALENDAR



Hilary Czarda  
Donate Life America



# Tactics

- Calendar
  - Consistency is key
  - **Proactive**, not just reactive
  - Track deadlines/timelines for planned content, stick to them

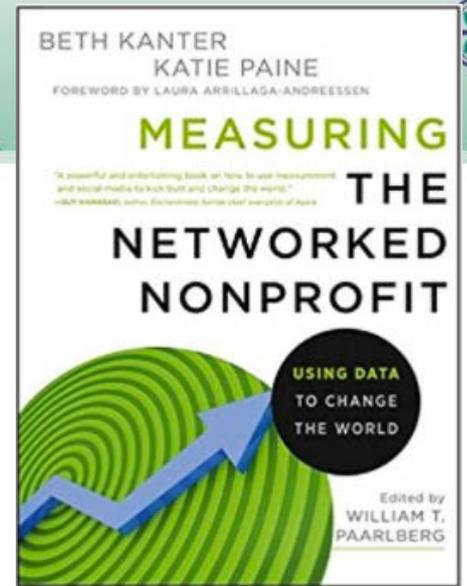


# Tactics



- Measurement
  - 7 basic steps\* - define your:
    - Goals
    - Audiences
    - Benchmarks
    - Metrics, get buy in (what does success look like?)
    - Time and costs
    - Data Collection tools
    - Collect, analyze and turn into action

\**Measuring the Networked Nonprofit* – Beth Kanter





# Tactics: How to maximize participation



## Current Participation

- 493 Members
- 24 in Spanish group

5 Aftercare staff are  
Administrators & Moderators

Members 491

Admins and Moderators 6

-  **Liliana Quinonez**  
Admin  
View 3 recent posts  
Works at OneLegacy
-  **Rebecca Lofthouse Msw**  
Admin  
View 3 recent posts  
Donor Family and Aftercare Specialist at OneLegacy
-  **Jennie Alicia Axelrod**  
Admin  
Aftercare Specialist at OneLegacy
-  **Tracy H. Chang**  
Admin  
View 1 recent post  
Aftercare Specialist at OneLegacy
-  **Anna Arellano Binder**  
Admin  
View 3 recent posts  
Studied at California State University, Long Beach
-  **Michelle Post**  
Admin  
Manager, Donor Family Aftercare at OneLegacy



# Tactics: How to maximize participation

**Identity relevant topics to post**

# Tactics: How to maximize participation

## OneLegacy Donor Family Facebook Group

### Topics – Memorial Tattoos!!!





# Tactics: How to maximize participation



## OneLegacy Group & Event Announcements

 **Liliana Quinonez** created a private event for the group. Admin · Yesterday at 1:25pm

**FEB 10** **OneLegacy Donor Family Aftercare grief support grou...**  
 Feb 10 - Jun 9 · 221 S. Figueroa St. Los Angeles CA 90012  
 11 Going · 12 Maybe · 8 Can't Go

Like

Comment

You and Rebecca Lofthouse Msw

 Write a comment...

 **Anna Arellano Binder**  
 Admin · January 24 at 4:35pm

Hello all! The Donate Life Run Walk will be held on Saturday, April 28th. Team captains of the Donor Family Teams from last year's Run Walk should be receiving their registration packets soon. They have been mailed out. If you did not participate last year and would like to receive a packet, please let us know and we can either mail or email a packet to you.

For those of you who have participated, how would you describe your experience to a family who is thinking about participating for the first time?



Like

Comment

You, Margarita Gonzalez, Carolyn Tomas and 25 others

[View 18 more comments](#)

 **Desiree Torrez Pacheco** Can you please send me a packet, we would like to participate. Thank you

Like · Reply · 5d

 Rebecca Lofthouse Msw replied · 1 Reply



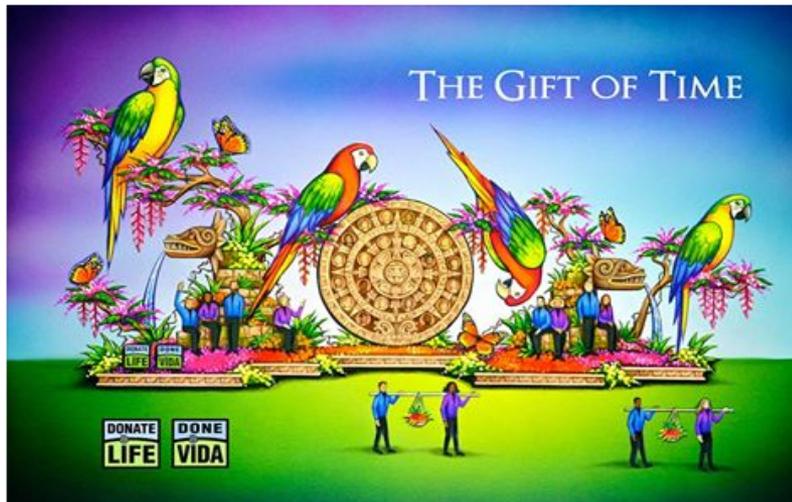
# Tactics: How to maximize participation



**Michelle Post** recommended [Donate Life Rose Parade Float](#).

Admin · October 30, 2017

[Donate Life Rose Parade Float](#) Announcement: As Tracy said earlier, the shifts are full and we are only taking waiting list names or UPS Float Decorators now. If you were a family who ALREADY registered to decorate the float, you will be receiving an email to officially register with our float company, Paradiso, online BY NOV 10th. If you wish to have button's made to wear for your decorating shift, you will need to send a photo to Kari by 11/15. Please look for that email from Kari Kozuki this week.



Like

Comment

Kari Lynn Lizana, Rebecca Lofthouse Msw and 12 others

[View all 4 comments](#)



**Michelle Post**

Admin · October 31, 2017

Super inspired about bringing a Family Grief Camp to WHITTER, CA for Organ, Eye and Tissue donor families. Looking forward to seeing 65+ children, teens and families of [OneLegacy](#) and [Comfort Zone Camp](#) this coming Saturday, 11/4 starting at 11:30am. Just completed leadership call with CZC staff! My heart is full. ❤️



Like

Comment

You, Margarita Gonzalez, Carolyn Tomas and 11 others

[View all 4 comments](#)



# Tactics: How to maximize participation



## Polls Feature

We asked for DF  
feedback

OL Eye Bank Wet-Lab  
and DFAC

Michelle Post created a poll in OneLegacy Donor Families.  
10 March · 🌐

Question of the Day: CLICK ON THE OPTION BELOW.  
From a donor family perspective, if your loved one gave **corneas** that could not be transplanted but the **corneas** could be used for research to train **cornea** surgeons on how to perform the proceed (which could help 100s of patients see in the lifetime of the surgeon's career), would you want a thank you note signed by the surgeons who attended the training and worked with your loved one's **corneas**? Even if your loved one did not do...  
See more

- Yes, this would be meaningful to me (and please post a comment about why below on the thread) +53
- Maybe (explain why below) +1
- I have no opinion either way (feel free to comment below) +1
- No, I would not be interested in this (and please post a comment about why below)

👍 Tami Christopher, Jami George and 8 others      32 Comments

👍 Like      💬 Comment



# Tactics: How to maximize participation

## Livestream



Rebecca Lofthouse Msw was live:  
Admin · January 12 at 11:24am

Self-Care in the New Year  
January 14th and 21st  
OneLegacy Donor Family  
Aftercare

81 Views

Like Comment

You, Michelle Post and 3 others

“I also think it is important to keep providing the live feeds ...For a society that has not been educated about grief and loss, when I found myself "in it" I was very hungry for information on how to navigate this traumatic event and OL was there”

Kari Lizana



# Tactics: How to maximize participation



Group Topics	Live stream views
“Diversity in Grief, How different Cultures Remember their Loved Ones”	<b>142 views</b>
“Planning for the Holidays”	<b>86 views:</b> opening discussion & 45: presentation
“The Gift of Time” OneLegacy 2018 Float Theme	<b>85 views</b>



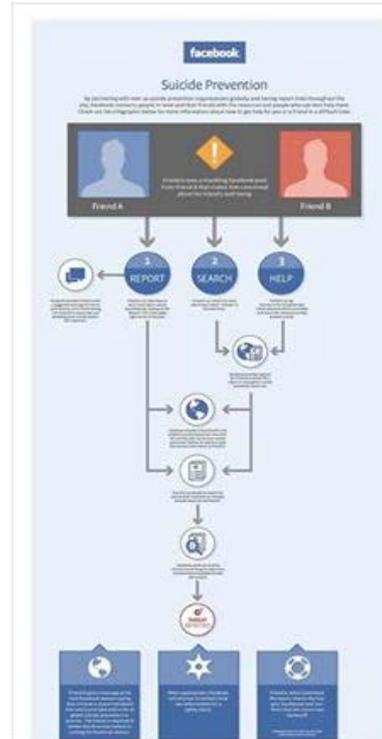
# HOW WE NAVIGATE CHALLENGING POSTS



**Michelle Post**

Admin · August 27, 2017 · Ladera Heights

If you are needing 24x7 support or concerned about a friend on Facebook or someone in your home... (877) 7CRISIS, 8777274747



**SUICIDE PREVENTION WEEK SEPT**  
**ur home Suicide-Pr**

**MEDICATIONS**  
Lock and limit.  
Fact: Teens who attempt suicide...  
Fact: Millions and teens...

**FIREARMS**  
Remove. Lock.  
Fact: Firearms are used in close to half of teen suicide deaths.

**SUPPORT**  
Listen up.  
Fact: Millions and teens...

#NSPW  
Bra

Like

Comment

Jennie Alicia Axelrod and 3 others

“ EVERYBODY HAS A DIFFERENT  
STORY TO TELL ON FACEBOOK BUT  
ITS ALL ONE MELODY WE ALL  
LOST SOMEONE WE LOVE”  
*CAROL CURTIS*



saving lives through organ, eye & tissue donation



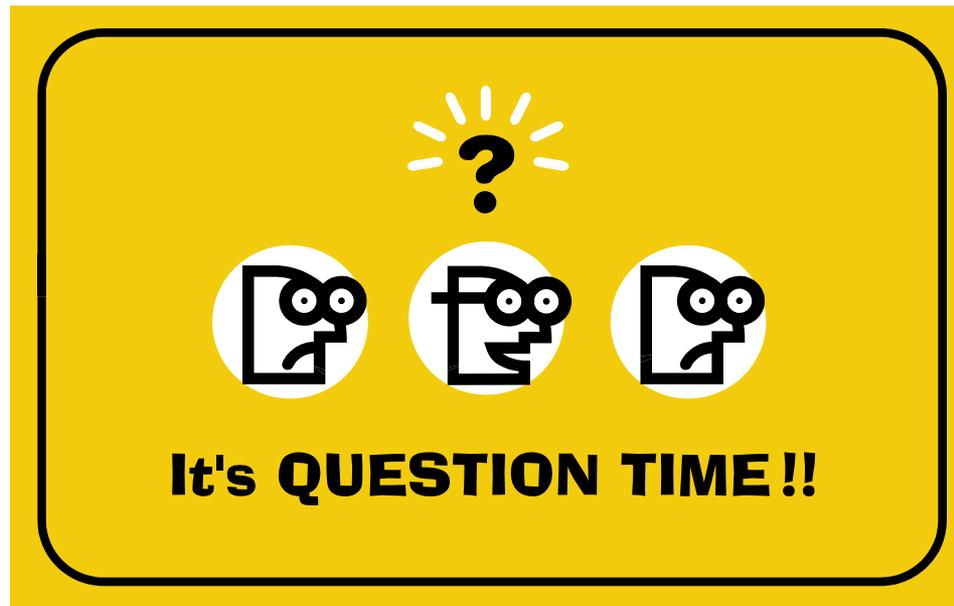
- IN THE PPT WITH DIANE/NHPCO  
FOLLOWING THE Q&A SLIDE=
- 1) TYPES OF FB PAGES DESCRIBED
  - 2) 13 STEPS FOR STARTING A FB GROUP
  - 3) OTHER ONLINE RESOURCES
  - 4) REFERENCES



saving lives through organ, eye & tissue donation



# Questions



Presented by Michelle A. Post, MA, LMFT  
Facebook/Google+: Michelle Post LMFT  
Twitter/Instagram: 1HeartHealerLA  
[www.Michelle-Post.com](http://www.Michelle-Post.com)



# Types of Facebook Pages



## 1) Fan Pages



### Pros:

- ❖ Tracks stats
- ❖ “Like” it = less labor in adding people
- ❖ Good for marketing, public education
- ❖ Fans can add other fans to the page

### Cons:

- ❖ Lacks control over who joins
- ❖ Lacks privacy
- ❖ Can create space for  
DFs and RCs to meet without due process



# Types of Facebook Pages



## 2) Group Pages

SORT ▾

### Create New Group

**Group Name:**

**Members:**

---

**Privacy:**

- Open**  
Anyone can see the group, who's in it, and what members post.

---

- Closed**  
Anyone can see the group and who's in it. Only members see posts.

---

- Secret**  
Only members see the group, who's in it, and what members post.

Jackie Buckley Moss TY, Debster!

# Types of Facebook Pages



## 2) Group Pages

a) Open = Anyone can see the group, who's in it, and what members post. (Lacks privacy)

b) Closed = Anyone can see the group and who's in it. Only members see posts.

c) Secret = Only members see the group, who's in it, and what members post. (The group is invisible and donor families cannot search for it)

# OPOs who had started FB “Donor Family Groups”



96 donor families as of June 2012  
“closed” group

Started by donor families  
Administrators: 1 staff, 2 DFs



92 donor families, as of June 2012  
“closed” group

Administrators: 5 Staff Members



## OneLegacy Aftercare Chose:



2) Group Pages – Decide what kind you want.

b) Closed = Anyone can see the group and who's in it. Only members see posts.



# OneLegacy Facebook History



OneLegacy Launch “Closed”  
Donor Family Facebook  
Group, June 2011

“OneLegacy Donor Families”  
150+ members as of May 2012  
Administered – 2 staff

2016?  
400 Members  
1 Admin, 5 people post

+ Create A Page

- Now
- May
- 2012
- 2011
- 2010
- 2009
  - December
  - November
  - October
  - September
  - August
  - July
  - June
  - May
  - April
  - March
  - February
  - January
  - Founded



<http://www.facebook.com/groups/206143099419312/?ref=ts>

# OneLegacy Group Member Feedback:



*It is a place for me to go and share my feelings about my daughter Sarah with people that have gone through what I have. I wouldn't know what to do without my facebook page.*

*~ [Rosanna Landeros](#)*

*I wish this had been here 12 years ago when my mom died. I don't feel like I'm bothering anyone with my sad days! It feels good sometimes just to write it down and vent!*

*~ [Kristine Croddy-Swertfeger](#)*

# TIPS for Getting Started



1. Research which Organizations (NAGC? Hospice?) are running FB Fan Pages and Group Pages or share this presentation with your organization to establish interest.
2. Create buy in from your organization.
  - ❖ Facebook is free
  - ❖ Staff time = administering, checking, responding, adding people, document, etc.  
E.g., 150+ people ~ 30-45m/day Mon – Fri + co-leader.
  - ❖ Also IT remove your FB block?

# TIPS for Getting Started



3. Create a FB Account w/ work email (Ethical considerations: minimize self-disclosure, dual relationships)
  
4. Recruit co-admin.  
Note: For groups, if possible w/ licensed mental health background (LCSW, LMFT, LPC, etc)
  
5. Decide what type of page you want (Fan vs. Group; and Open, Closed, or Secret Group).



# TIPS for Getting Started

## 6. Develop a process and/or P&P about:

- Who can join
- How to add someone
- Staff coverage
- Tracking disclosure/guideline agreements
- Staff use of Social Media (see 2 examples: LAORA, LifeLink GA –MP can email you samples)

# TIPS for Getting Started

## 6. Example Process at OneLegacy:

- Open to all OL DF members & adopted DFs who live in our DSA (Not a recipient group)
- DF must email 1) name of donor, and 2) name of the DF (we verify already a part of our DB)
- We email disclosure to participant (Get permission from APs to add additional DFs)
- Get written reply (& save emails in FB file)
- Note in DF electronic records.
- Staff coverage – 1 person checks daily & replies when necessary. All admins get emails.

# 6) Process Improvements for group registration



<http://www.thelf.org/support/facebook.html>

The screenshot shows the website for the Living Legacy Foundation of Maryland. The header includes the logo, navigation links (News & Events, Contact Us, en Español), and a 'Register to BE A DONOR' button. A search bar is also present. The main navigation menu includes: About Our ORGANIZATION, The Organ and Tissue DONATION PROCESS, Extraordinary PEOPLE, support for DONOR FAMILIES, Resources for RECIPIENTS, and Learn How YOU CAN HELP. The page title is 'Donor Family Facebook Page'. The text describes the group as a Facebook 'Secret' group for donor families. A registration form is visible with fields for: Your full name \*, E-mail address associated with your Facebook Account: \*, Your phone number \*, and Donor's full name \*. A photo of a woman holding a framed portrait of a man is shown. A quote reads: 'Knowing how her life had been dramatically changed by donation, Danette immediately knew someone else's life would be changed'.

[www.MyContactForm.com](http://www.MyContactForm.com) (Free)

# TIPS for Getting Started

- 
7. Develop a disclosure/disclaimer/terms and conditions form and run it by your legal or QA  
(see 3 examples: Life Alliance (LAORA) →  
OneLegacy →  
Living Legacy Foundation (LLF)  
MP can email to you)



# TIPS for Getting Started



8. Develop a plan for launching and notifying families
  - OL – Newsletter & Aftercare Mailings
    - Announced at Aftercare Grief Support Groups, Ceremonies, Events
    - Fan pages
    - Volunteer Distribution list
    - 1<sup>st</sup> calls
    - Add to all materials/website/emails

**9) Create the Group!!!**



# Create the Group!!!



facebook

Search

Michelle Post Mft Home



Michelle Post Mft

Update Status Add Photo / Video Ask Question

What's on your mind?

1: Click Home

FAVORITES

News Feed

Messages 8  
Events 6

GROUPS

OneLegacy Donor Families  
Comfort Zone Camp ... 7  
ONELEGACY-Organ & Tissu...  
Psychotherapist Net... 4  
Create Group...

APPS

BranchOut  
MyCalendar - Birthd... 4  
Apps and Games 20+  
Pokes

Create New Group

Group Name:

Members: Which people do you want to add to the group?

Privacy:

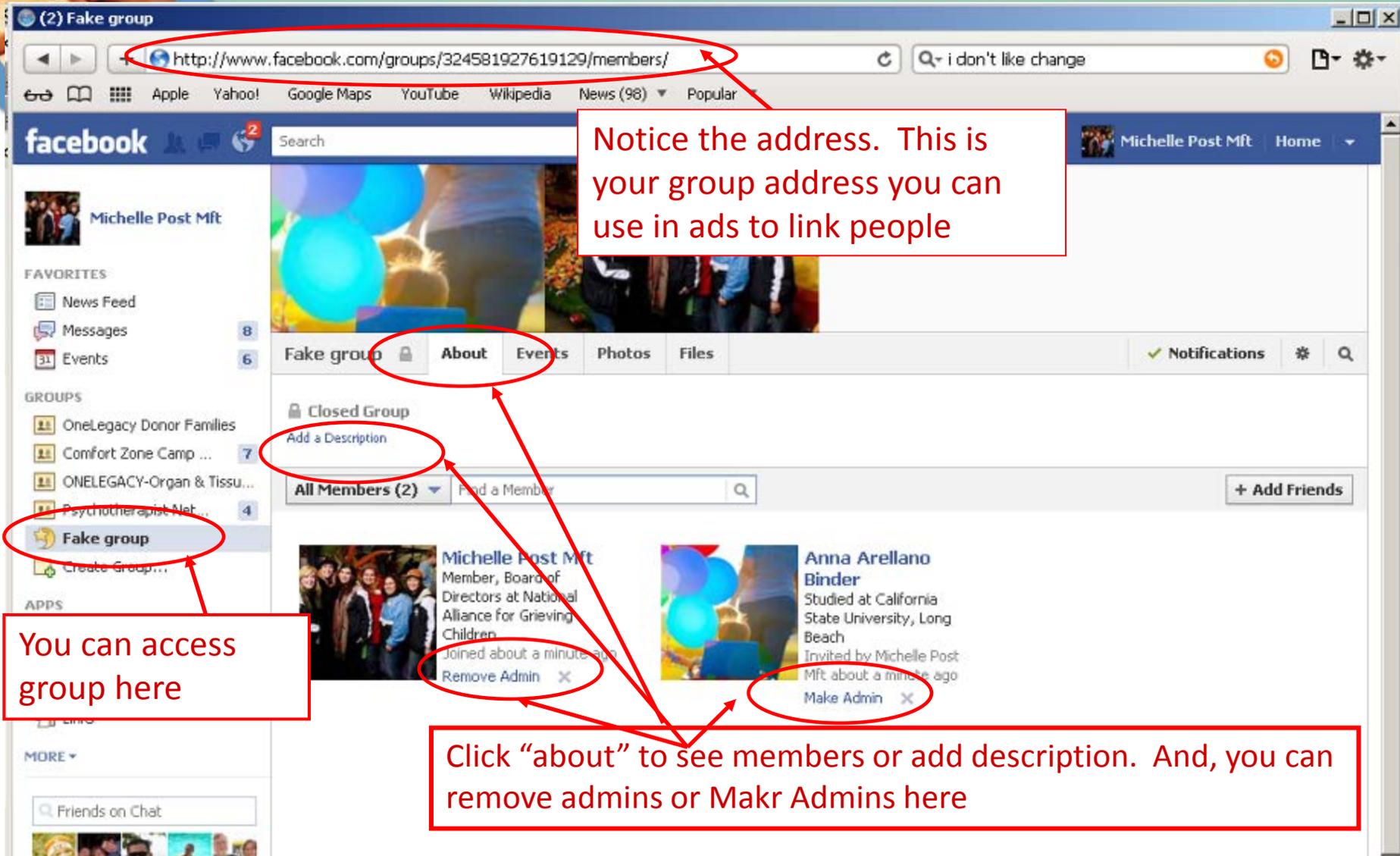
- Open  
Anyone can see the group, who's in it, and what members post.
- Closed  
Anyone can see the group and who's in it. Only members see posts.
- Secret  
Only members see the group, who's in it, and what members post.

Create Cancel

2: Click "Create Group:"

3: This window pops up, select group name, don't add members until ready, but make sure you have a colleague you can add or it won't create the group, select "Privacy type" of group you would like to add, and click "Create".

# Create the Group!!!



The screenshot shows a Facebook browser window with the URL <http://www.facebook.com/groups/324581927619129/members/> circled in red. The page title is "(2) Fake group". The left sidebar shows the user profile "Michelle Post Mft" and a list of groups, with "Fake group" highlighted in red. The main content area shows the group name "Fake group" with a lock icon, and tabs for "About", "Events", "Photos", and "Files". The "About" tab is selected and circled in red. Below the tabs, it says "Closed Group" and "Add a Description". There is a search bar for members and a "+ Add Friends" button. The member list shows two members: "Michelle Post Mft" and "Anna Arellano Binder". The "Remove Admin" button for Michelle Post Mft and the "Make Admin" button for Anna Arellano Binder are circled in red. A red box at the bottom contains the text: "Click 'about' to see members or add description. And, you can remove admins or Make Admins here".

Notice the address. This is your group address you can use in ads to link people

You can access group here

Click "about" to see members or add description. And, you can remove admins or Make Admins here

# OneLegacy Group



http://www.facebook.com/groups/206143099419312/members/

group address

Michelle Post Mft

FAVORITES

- News Feed
- Messages
- Events

GROUPS

- OneLegacy Donor Fami...**
- Comfort Zone Camp
- ONELEGACY-Organ & Tissu...

You can access group here

**OneLegacy Donor Families** About Events Photos Files

**Closed Group**

Welcome! This is a private, closed group for OneLegacy Donor Families to support one another. It is administered by OneLegacy Aftercare Staff. In order to participate, you must read and agree to the guidelines in our disclaimer AND you must be a friend or family member of a OneLegacy Donor or a OneLegacy staff member involved in organizing our Ambassador Program or Donate Life/OneLegacy events in which Donor Families participate. Please send our admins (Michelle Post or Anna Arellano) a private message with the full name of your donor and his/her date of birth if you would like to join this group. We will reply and send you the disclaimer. [Edit Description](#)

All Members (150) Find a Member

Michelle Post Mft  
Member, Board of Directors at National Alliance for Grieving Children  
Joined over a year ago  
[Remove Admin](#)

Sky Richelle Wilson  
Wifey & Mommy at Wilson Household  
Joined about 11 months ago  
[Make Admin](#)

Search for members here

# OneLegacy Group



Facebook

Search

Michelle Post Mft Home

Michelle Post Mft



OneLegacy Donor Families About Events Photos Files Notifications

Write Post Add Photo / Video Ask Question Upload File

150 members (2 new) Chat

Write something...

+ Add Friends to Group

Add people here by typing a "friend's" name



Bethany Vogel

I know I haven't posted or commented on this page in a while, but I'm still here and thankful for your encouragement & support because it's helped me find comfort....  
It's almost 3yrs since my husband, Erich R. Vogel passed away from a sudden heart attack, we were married just shy of 5 yrs, he was my best friend, a wonderful Daddy, my laughter, and my biggest supporter. When he died my world stopped & was flipped upside down (as I'm sure for most of you) I feel like most days I am able to do what needs to be done, and am starting to take control of my life again, but he is still always on my mind. Lately I have felt more lonely, now life has been very hectic & stressful so I'm sure this is adding to it.  
Today I had another really hard day, that is now turning into one of those

Requests (4) See All

	Amber S. Angers	✓	✕
	[redacted]	✓	✕
	Rosalinda Rodriguez-Ortiz	✓	✕

Or approve or message those who have found you and are requesting to join the group. We message them asking for donor name, check our records and send the disclaimer explanation before we approve an add.



# TIPS for Getting Started



## 10) Consider adding FAQ pages

- Aftercare Services and Events
- Disclaimer
- How do I contact My Loved One's Recipients
- How to request Organ/Tissue update
- What Grieving Children Really Need

Yes?

No?

# TIPS for Getting Started



- 11) Decide when you respond publically vs. private message (Ethics/Group Facilitation issues):
- Most often, OL publically. Transparency = key especially when resolving a posted complaint
  - Specific details of a donor case, privately (as outlined in our disclaimer)
  - Clinically urgent matters, both.



# TIPS for Getting Started



## 12) Calendar activity

- Friend people and once a week, announce to group.
- Tag to acknowledge birthdays on Facebook reminders. Our group is so big now that we do one a week and mention everyone with bdays.
- a few times a week post a comment, topic, announcements, new book, quote about grief, or donation related news whatever they might relate to. Ask people to comment. (We do it daily now)



# TIPS for Getting Started

12) Continued... Example Topics. Post questions that will get group talking to one another

Ex., In the beginning, have people tell their story. Then, once people keep joining, start a thread for all parents to post... all siblings... friends... children of parents who died... spouses or partners...all teens... all middle schoolers... cause of death... etc.



# TIPS for Getting Started



## 12) Topics (Continued)

- What emotions have you felt since the person died and how have you coped?
- What gets you out of bed in the morning and helped give you energy to try?
- If you could have one more day with the person who died, what would you do or say?
- What music reminds you of the person who died ?



## 12) Topics – What to do on Anniversaries/Special Days

This weekend is 2 years since David's death. He was 10. It's an emotional time, but we're hanging in there. Any ideas on how to commemorate the day? I don't want to sit around moping all day. I'd prefer to do something uplifting. I'm thinking this group might have some ideas.

- Make his favorite dinner
- Do something he would have enjoyed
- Volunteer in his memory
- “I will be thinking of you. If you need a friend, I am here”

## 12) Topics – What to do on Anniversaries/Special Days

Thanks everyone. Here's what we chose...all things David loved.

- going to his favorite breakfast place.
- make lunches for our homeless here in town.
- Also going to a football game where the league he used to play for at halftime, they'll run/walk a lap in his honor... David was nicknamed "Lionheart" as he never quit. Should be a nice weekend celebrating a wonderful boy. May I continue to believe life is a gift and move forward.



# 12) Topics – Memorial Tattoos!!!



## Kristine Croddy-Swertfeger

Do any of you have tattoos in honor of your loved ones? I want to get on my foot in memory of my mom a butterfly! I dont have any tattoos at all btw!! Any suggestions or pictures?

Unlike · Comment · Unfollow Post · Yesterday at 4:18pm via mobile

You like this.



**Raquel Lynn Gonzalez** I am going to get one eventually. My daughter loved dragonflies, so I think I am getting a Deagonfly with the green organ donor ribbon on the inside of my wrist. Just have to come up with the design and courage to do it. LOL

Yesterday at 4:31pm via mobile · Like · 1



**Kristine Croddy-Swertfeger** Thats my problem too! My mom has been gone for almost 13 years. Its time for me just to do it!

Yesterday at 4:32pm via mobile · Like



**Alejandro Parajón** I've been trying to figure out and plan a design that will honor my mom as well. I have no tats too.

Yesterday at 4:51pm via mobile · Like · 1



**Ana Nolasco-Subias** I didnt like tattoos at all but I lost 3 family members in horrible ways and now I have 5. On my ankle I got the crown of thorns and all 3 names in surrounding the crown. From what I understand dragon flies are things people get to honor loved ones

Yesterday at 4:53pm via mobile · Like · 1



**Kristine Croddy-Swertfeger** Alejandro what have you thought of getting! Ana are the names big? I have heard about dragon flies but ive always liked butterflies and roses.



## Ana Nolasco-Subias

Yesterday at 5:



## Robert Shepa

def/bass def ini couple months a

Yesterday at 5:



## Alejandro Parajón

thinking the sup out her initials o donate life writi

Yesterday at 5:



## Maria Dolbin

my stepdaughte 23 hours ago · L



## Nikki Richardi

and his name fo was always the different places 23 hours ago · L



## Nikki Richardi

23 hours ago · L



**Rena Carson Shillings** Yes, I have a crown for Pat and an initial "P"

23 hours ago · Unlike · 4



**Debbie Solis** I've got a heart with wings with my son's name and the year of his birth and death.. On it too, it says, "Forever in my heart." It was done 4 days after he was buried.. His father and ex





# 12) Topics/Threads

Anxiety about other people dying and how to cope

Sharing about experiences with medication

Anniversary Reactions



# 12) Topics/Threads



Welcoming new group members/General support

Dealing with finding things in the deceased belongings

Books, movies, poems, plays and resource materials

# 12) Topics/Threads



## Keeping the deceased's cell phone active/listening to old saved messages

*I know that this is probably not good....probably all the experts on death would say I am wrong BUT it works for me, so why do I have to stop? My Son was killed over 4 years ago but I still pay his cell phone bill every month. Why?? So I can still call it and listen to his voice mail message and also....I keep thinking he will call me. I will not shut off his phone. No one in my family knows that I am doing this, or if they have called his number, maybe they know and do not want to upset me so they say nothing. This is my LifeLine to him, is that so wrong? I feel that my Son would be saying: "MOM, you are wasting money every month" and he would do his great laugh and I would smile :-)*

[Joan Ahern](#)



# TIPS for Getting Started



## 13) Remember to say “Thanks”

- Click “like” to support people for sharing
- Share good comments with colleagues as a thank you for their hard work
- Share group members’ Thank yous with your Manager/Management team/Board



# Other Ethical Considerations?



- Back up plan for staff changes?
- Digital fingerprint/will?
- Risk management?
  - Reality is it's happening with or Without us  
"Saved my life" ~ Nikki



# Great online resources?

- 
- [www.HealGrief.org](http://www.HealGrief.org)
  - [www.WhatsYourGrief.com](http://www.WhatsYourGrief.com)
  - [www.ChildrenGrieve.org](http://www.ChildrenGrieve.org) (NAGC)
  - [www.ADEC.org](http://www.ADEC.org) – therapist look up
  - [www.ModernLoss.com](http://www.ModernLoss.com)
  - [www.SolaceClub.com](http://www.SolaceClub.com) – bereavement gifts instead of flowers
  - <http://www.deathreferencedesk.org/>
  - [www.OpenToHope.com](http://www.OpenToHope.com)
  - [www.GriefNet.org](http://www.GriefNet.org) – subscription listserves
  - [www.DyingMatters.org](http://www.DyingMatters.org)
  - [www.childbereavementuk.org](http://www.childbereavementuk.org)
  - [www.Death Café.com](http://www.DeathCafe.com)
  - [www.Griefincommon.com](http://www.Griefincommon.com) (like match.com without dating component)
  - <https://optionb.org/> - groups online

# References



Brondou, C. (2010, September 28). Grieving 2.0: As students turn to Facebook to mourn, how should parents, teachers, and counselors react? Retrieved from <http://www.findingdulcinea.com/news/education/2010/march/Grieving-2-0--As-Students-Turn-to-Facebook-to-Mourn--How-Should-Parents--Teachers-and-Counselors-React-.html>

Falconer, K., Sachsenweger, M., Gibson, K., & Norman, H. (2011). Grieving in the internet age. *New Zealand Journal of Psychology, 40*(3), 79-88.

Feiler, B. (2016, October). The Art of Condolence. The New York Times. Retrieved from <http://www.nytimes.com/2016/10/02/style/how-to-express-sympathy.html?mwrsm=Email>

Frost, M. (2014). The grief grapevine: Facebook memorial pages and adolescent bereavement. *Australian Journal of Guidance and Counselling, 24*(2), 256-265.

Gillespie, M. (2016). Social Grief: How Teens are Using Social Media to Talk About Grief [PowerPoint slides]. Retrieved from [www.ChildrenGrieve.org](http://www.ChildrenGrieve.org).

Hortobagyi, M (2007). Slain students' pages to stay on Facebook. *USA Today*. Retrieved from [http://www.usatoday.com/news/nation/2007-05-08-facebook-vatech\\_N.htm](http://www.usatoday.com/news/nation/2007-05-08-facebook-vatech_N.htm)

\*\*Hoy, W. G. (2016). Bereavement Groups and the Role of Social Support: Integrating theory, research, and practice. Routledge. New York, NY.



# References



James, L. (2014). *Continuing bonds in a virtual world: The use of Facebook in adolescent grief*. Retrieved from UMI Dissertation Publishing. (UMI 3635630).

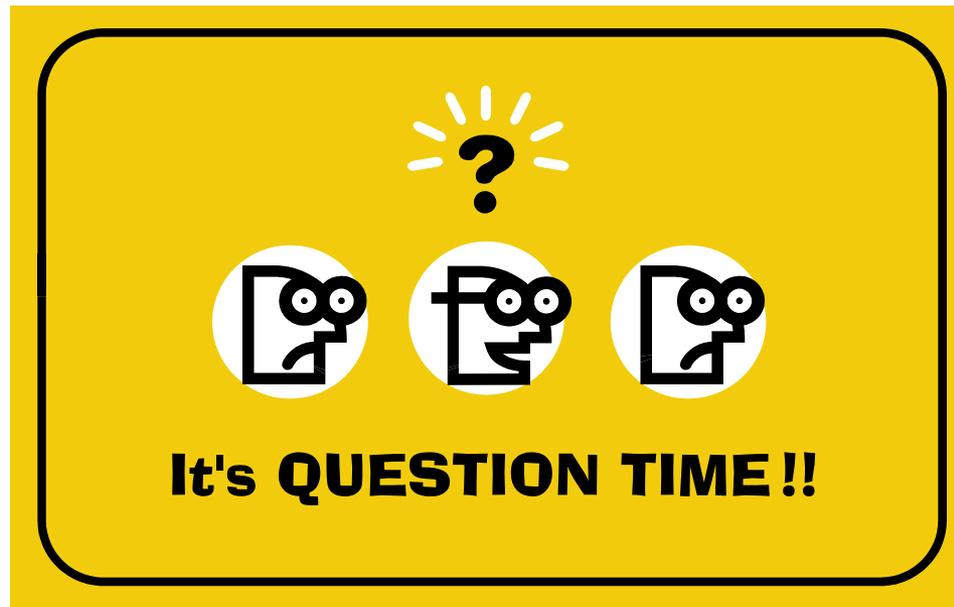
Lenhart, A. (2015, April 9). Teens, social media & technology overview 2015. Retrieved from <http://www.pewinternet.org/2015/04/09/teens-social-media-technology-2015>

Moore, J. (2011). Facebook and the new face of grieving. *The Denver Post*. Retrieved from [http://www.denverpost.com/lifestyles/ci\\_18406452](http://www.denverpost.com/lifestyles/ci_18406452).

Petrecca, L. (2012, May). Mourning becomes electric: Tech changes the way we grieve. *USA Today*. Retrieved from <http://www.usatoday.com/money/industries/technology/story/2012-05-07/digital-ourning/55268806/1?sf4452458=1>

\*\*Sofka, C., Noppe Cupit, I., Gilbert, K. (2012). *Dying, Death, and Grief in an Online Universe: For Counselors and Educators*. New York, NY: Springer Publishing.

# Questions



**It's QUESTION TIME !!**

