

# Celebrating the Sibling Voice

2017 National Sibling Leadership Network Conference

June 24 & 25, 2017

Hartford Convention Center  
Hartford, CT



**SIBLING LEADERSHIP NETWORK**

**10 Years Strong!**





**WELCOME  
to the  
2017 National SLN Conference!**

**THE MISSION**

**of the Sibling Leadership Network (SLN)**  
is to provide siblings of individuals with disabilities the information, support, and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families.

## SPECIAL THANKS TO OUR SPONSORS

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Shea Tanis

## HISTORY OF THE SLN

The SLN was founded in 2007 after seeing a need for more of a focus on siblings of people with disabilities. Here are highlights from over the years:

- **2007:** SLN was founded and held its first national conference in Washington, DC in November in conjunction with the Association of University Centers on Disability (AUCD) conference.
- **2008:** SLN held second national conference in Columbus, OH which culminated in the creation of a policy Whitepaper published with recommendations for research, advocacy and supports related to siblings.
- **2009:** A leadership meeting was held in Washington, DC in November and the first official Board of Directors was created for the SLN.
- **2010:** SLN incorporated as a nonprofit organization and also held an International Sibling Conference in Greenwich, CT.
- **2011:** A leadership meeting of the SLN Board was held in Nashville, TN where a strategic plan was developed for the future of the organization.
- **2012:** The SLN hired the first part-time Executive Director to grow the organization and a virtual leadership meeting of the Board was held.
- **2013:** The fourth National SLN Conference was held in Pittsburgh, PA in conjunction with the American Association on Intellectual and Developmental Disabilities (AAIDD).
- **2014:** SLN built organization structure and focused on chapter development, building partnerships, engaging members, and planning the 2015 Conference.
- **2015:** The fifth National SLN Conference was held in Louisville, KY in conjunction with AAIDD.
- **2016:** The SLN grew organizational capacity and hired a Communications Consultant and a Project Manager.
- **2017:** The SLN celebrates 10 year anniversary and holds sixth National SLN Conference in Hartford, CT.

## AGENDA

**Saturday, June 24, 2017**

**8:30 a.m. Registration and breakfast (provided)**

**9:00 a.m. Welcome and Introductions**

**9:15 a.m. SLN: Engaging and Empowering Siblings Together**  
*Katie Arnold, SLN Executive Director*

**10:15 a.m. Break**

**10:30 a.m. Morning Breakout Sessions (choose one of the four options below)**

**A. Planning for the Future: The Sibling Roadmap (Main Conference Room)**

*Speakers: Katie Arnold, SLN Executive Director and Amy Halm, SLN Project Manager*

Hear from two siblings about planning for the future with your whole family. You will learn about how to get the difficult dialogue started in your family, the process of future planning, and an overview of the areas that are important to consider for planning. Resources will be shared that can help families plan and navigate the process.

**B. Exploring Current Research About Siblings of Individuals with Disabilities (Room 22)**

*Moderator: Meghan Burke, SLN Chair of Research Committee, Assistant Professor Department of Special Education, UIUC*

*Speakers: Chun-yu Chiu, Assistant Professor in Special Education, National Taiwan Normal University, Chung eun Lee, Doctoral Student, Department of Special Education at UIUC, Ariella Meltzer, Research Associate, Social Policy Research Centre and Centre for Social Impact at the University of New South Wales in Sydney, Australia*

This presentation will feature three international researchers presenting their current studies about siblings. Notably, each presenter is a sibling herself.

Presentations will include:

- A Qualitative Exploration of Work-Family Spillover Experience from Special Siblings with a Career in Special Education by Chun-yu Chiu
- Correlates of Current Caregiving and Other Roles for Siblings of Adults with Intellectual and Development Disabilities by Chung eun Lee
- Reflections and research on what it means and what it takes to support the sibling relationship by Ariella Meltzer

**C. Connecting & Engaging with Sibs Locally: State Chapter Development (Room 23)**

*Speakers: Emily Ladau, SLN Digital Communications Manager and Erin Sweeney Hutzelman, SLN Co-Chair of Network Development*

Interested in starting a SLN chapter in your state? This session will provide information on how to use the SLN Chapter Guide to create and sustain a state chapter. It will also address how to use social media for outreach and to bring new members into your chapters. Lessons learned from current state chapters will be provided.

**D. Cops, Safety, and the Dignity of Risk (Room 24)**

*Speakers: Nora Fox Handler, Supporting Illinois Brothers and Sisters (SIBS) and Bruce Handler MD, Assistant Professor, College of Medicine, UIUC; Instructor Crisis Intervention Team Training, Cook County Sherriff's Bureau of Training and Education, Shaquinta Richardson, PhD Candidate, Institute on Human Development & Disability, University of Georgia*

Living in the community involves the dignity of risk. This session will include information on Crisis Intervention Team training for police. How to advocate for CIT training in your community and safety tips for self-advocates and family members. Perspectives from siblings regarding policing of siblings with disabilities will also be shared.

**11:45 a.m. Break**

**12:00 p.m. Lunch provided**

**12:45 p.m. Kelly's Hollywood: A Candid Portrayal of a Sibling Relationship**

*Keynote speaker: Brian Donovan – Filmmaker, Actor, and Producer*

Brian is the creator of the award winning documentary, Kelly's Hollywood. Honest and raw, the film tells the intimate story of Brian, an aspiring actor who brings his sister Kelly, born with Down syndrome, out to L.A. to pursue her dream of becoming a Hollywood diva. But as her health begins to fail and she becomes increasingly jealous of his fiancée, he is forced to confront his co-dependent sibling relationship and the threat it is posing to his engagement. Brian states: "There's a saying, 'love is the only true adventure', I would add, 'making a movie about love is the only true adventure'. When I picked up the camera 15 years ago and started shooting my sister Kelly, I didn't have much of an agenda. I was capturing moments in her life that intrigued and inspired me, but when those moments started to affect me more directly, I got more serious about making this film. I had a unique perspective on an intimate relationship with a disabled sibling, so intimate that my romantic relationships became increasingly complicated and constrained, leading me to this exploration on human connection, commitment and the choices in life that effect one's fate." <http://www.kellyshollywood.com/>

**2:15 p.m. Break****2:30 p.m. Afternoon Breakout Sessions (choose one of the four options below)****A. Diversity and Social Justice in the Sibling Movement (Room 23)**

*Speakers: Nick Perry, Director of Developmental Disabilities Services – East, DeKalb Community Service Board and Alison Whyte, Program Development Specialist at the DC Department on Disability Services; Co-Chairs of the SLN Diversity and Social Justice Committee*

This session will explore diversity and social justice issues through the lens of sibling identity. We will discuss how our sibling identities interact with other important parts of our identities and how we can, as advocates with our siblings with disabilities, connect with other social justice movements that are important to our diverse community. We invite you to join us as we learn together, aim to create a respectful space that honors all voices, and views conflict as an opportunity to grow.

**B. National Disability Policy in 2017 (Room 22)**

*Speakers: Rachel Patterson, Senior Consultant, Health Management Associates and SLN Chair of Policy & Advocacy Committee and Nicole Jorwic, Director of Rights Policy, The Arc of the United States*

What's going on? What will happen to my sib's services? How can I get involved? If you've asked these questions, come to this session for national policy updates and tips on how siblings can best make our voices heard to protect services and improve disability policy.

**C. How Do I Best Support My Sibling? An Overview of Decision-Making Options (Main Conference Room)**

*Speakers: Robin Shaffert, Senior Executive Officer, Individual & Family Support, The Arc of the United States and Liz Mahar, Program Manager, Individual & Family Support, The Arc of the United States*

Siblings play a big role in providing decision-making support; some serve as guardians to a sibling with an intellectual and/or developmental disability (I/DD). Many families are told that guardianship is necessary, but less restrictive alternatives should be tried and found ineffective before guardianship is considered. Learn from The Arc's Center for Future Planning about ways to support siblings with I/DD to make their own decisions (informal advice, powers of attorney, supported decision-making). By sharing personal experiences of supporting a sibling across the country, we will explore ways to help your sibling build decision-making capacity through education, supports, and life experience.

**D. Family Dynamics: Successes & Struggles (Room 24)**

*Moderator: Sara Hansen, SLN Vice Chair and Special Education/Deaf Education Specialist in the Wagner School District.*

*Panelists: Emily Holl, SLN Secretary, Jaime McGeady, SLN Treasurer and Community Supports Educator, Barbara Sapharas, SLN Board Member, and Jalyynn Schmitz, SLN member and Elementary Special Education Teacher*

This breakout session will discuss several topics related to families including choosing a life partner, genetic testing, becoming a parent, kinship and foster care, adoption, intrafamilial roles, healthy boundaries, conflict management, self-care, and incorporation of others in future planning. Panelists will share personal experiences with tough conversations and ways to resolve conflict when possible. We will also investigate the intricate balance between parents and siblings as well as siblings and their nieces, nephews, aunts, uncles, and cousins.

**3:45 p.m. Break**

**4:00 p.m. Celebration of the 10 year Anniversary of the SLN (Main Conference Room)**



Join us to celebrate the SLN turning 10 years old! This will be a fun celebration with drinks and cake. Chat and connect with fellow siblings and sibling supporters.

Commemorative Tribute and Toast will be given by  
*Don Meyer, Director, Sibling Support Project*



Silent Auction – Please look at the tables with silent auction items and place your bids. Have fun trying to outbid each other and raise money for a good cause - to sustain and grow the SLN organization. Cash and personal checks will be accepted. The silent auction ends at 5pm and winners will be announced.

**5:15 Conference program concludes for the day**

**Dinner on your own** – feel free to connect with other conference attendees and find a restaurant of your choice to enjoy dinner in Hartford.

**Sunday, June 25, 2017**

**8:30 a.m. Breakfast provided**

**9:00 a.m. Table Talks and Micro-learning session**

*There are many exciting sessions during this time for you to choose from.*

*Option 1: Attend the 1 hour micro-learning breakout session in Room 23*

*Option 2: Participate in two of the table topic discussion in the main conference room - 20 minutes each – you choose to sit at one table for your first discussion and then switch to a new topic for the second part of the time.*

**OPTION 1:**

**1 Hour Micro-Learning Session**

**Educational Pop Rocks: Using Micro Power Bursts to Maximize Learning** (Room 23)  
*Carol Blessing, LMSW, Project Director, SiblingResources & Faculty, Cornell University*

This learner-centric approach to knowledge transfer puts the learner in control of their learning path. Information is delivered “just in time” because they decide what they want to learn and when they want to learn it. This interactive session will showcase examples of the micro-learning model, highlight benefits and suggest ways in which the model can be used to share information and resources. Participants will be invited to Celebrate the Sibling Voice by sharing thoughts, ideas and opinions about micro-learning as a beneficial learning tool.

**OPTION 2:**

**Table Talks – choose two of the nine topics to participate in for 20 minutes each**  
(Main Conference Room tables)

**A. Club Sandwich Generation - Juggling Multiple Caregiving Roles**

*Tamar Heller, Distinguished Professor and Director of Institute on Disability and Human Development, University of Illinois at Chicago, Co-Founder of SLN; Emily Shea Tanis, PhD., Associate Director, Coleman Institute for Cognitive Disabilities, University of Colorado, Assistant Professor, Department of Psychiatry*

“The Sandwich Generation” is a term that is often used to describe people who are caring for their aging parents and their own children. Adult siblings often have an extra layer, when they play a caregiving role for their sibling as well. Please join the conversation with two SLN Board members who will discuss the challenges and rewards of managing multiple caregiving roles.

**B. Supporting Young Brothers and Sisters***Don Meyer, Director, Sibling Support Project*

Because sibling issues are lifespan issues, brothers and sisters will have unique concerns throughout their lives. Too often, however, siblings only connect with others who “get it” as adults. At this Table Talk, we’ll discuss how to create support opportunities for an especially deserving community: young brothers and sisters.

**C. Self-Advocacy Perspectives from Siblings with Disabilities***David Horton, SLN Past Chair of the Board, and Eric McVay, SLN Board member representing Self Advocates Becoming Empowered*

The SLN includes siblings with and without disabilities. Come discuss the perspective of the sibling with disabilities. Learn more about Self Advocates Becoming Empowered and ways to support self-advocacy. Discuss ways to enhance advocacy and self-advocacy together.

**D. Sib-in-laws: Walking the tight rope of relationships with your spouse, your in-laws and yourself. Time of your life or living time? Observations and clues to success.***Bruce Handler MD, assistant director for crisis training at the Cook County Sheriff’s Department of Training and Education, Cook County, Illinois*

I’ve been a sib-in-law for over 36 years (and before that, 4 years as a sin-in-law). Over that time, dating, marriage, children, career and parent issues often paled in contrast to sibling/family issues that emerged. I’m sure you have experiences of your own, bring them to our table and share the uniqueness of being a sib-in-law.

**E. Interacting with Health Care Professionals: Promoting Quality Support for Siblings Through Collaboration***Nathan Grant, President and Founder of Siblings with a Mission*

Growing up, siblings often attend numerous doctor appointments with their brother or sister. While it is these doctors that siblings often turn to first in search of support, many health care professionals do not know how to provide the unique care that siblings need. This session will provide stories that highlight how siblings can best interact with health care professionals. By presenting an overview of work conducted by Siblings with a Mission, SLN, and previous psychosociological research, this session will offer siblings an opportunity to exchange perspectives and find suggestions for how to receive the best support possible from multiple resources.

**F. Pennsylvania Sibling Support Network (PSSN) & Sibling Ambassadors Program***Lynne Mack, Andrea Powell, and Nanette Holley, PSSN Leaders*

The Sibling Ambassadors Program in Pennsylvania is an innovative program that allowed PSSN to collaborate with SLN and Temple University to develop a 2 day leadership training that brought together 21 siblings from across the state. These Sibling Ambassadors developed action plans to build the PSSN network and grow sibling support in their regions. Presenters will share the successes of the training program and the continued growth of sibling support that progresses in Pennsylvania.

**G. Love, Marriage and Baby Carriages: Unique Challenges and Opportunities for Sibs***Emily Holl, SLN Secretary & Co-editor of "The Sibling Survival Guide"*

As we search for love and contemplate partnership and parenthood, siblings of individuals can encounter unique challenges and opportunities. This informal, interactive table talk will explore how we can navigate our roles in romantic relationships and balance our own needs as caregivers on the road to Happily Ever After.

**H. Get Involved with the Sibling Leadership Network***Ed O'Neill, SLN Chair*

We hope that the Conference has inspired you to become more involved in the SLN! Learn more about leadership roles and committee membership in the SLN. Hear first-hand from the SLN's Board Chair about how to become more engaged in the sibling movement.

**I. Being a Sib and LGBTQIA (lesbian, gay, bisexual, transgender, queer, intersex, asexual)***Alison Whyte, Co-Chair of the SLN Diversity and Social Justice Committee*

This table talk will be an opportunity for LGBTQIA sibs to share experiences about their own gender or sexuality journey. What was coming out to your family like (and it's okay if that hasn't happened yet!)? Does your sibling understand your gender or sexuality? How do you find support and community as an LGBTQIA person? Allies are invited to join this table talk as listeners who come to gain a deeper understanding of the unique experience of LGBTQIA sibs.

**10:00 a.m. Hurricanes, Heartache & Hope: The Marvelous Martin Sisters**

*Keynote Speakers: Kimberley A. Martin, N.Y. Jets Beat Writer (Newsday) and Melanie Martin, YAI Member on the Autism Spectrum*

Sibling relationships are as complex as they are rewarding. But the dynamics of those bonds are tested even more so when one child has special needs. In that way, the relationship between Kimberley and Melanie Martin is no different from any other sib connection. Though raised by the same West Indian parents, both Martin girls required different forms of attention, love and nurturing during their formative years. And while they were brought up in the same house, their needs were quite different. But despite their divergent paths in life, Kimberley and Melanie managed to establish their own identities. And now, even in their 30s, they continue to showcase their individuality through their unique interests and various forms of art and expression. Through funny anecdotes and visual components, Kimberley and Melanie will share how they've strived in spite of an autism diagnosis -- one that was given decades before the disorder became a household word.

**11:00 a.m. State Sibling Chapter Discussions**

Meet with other attendees from your state to discuss the work of your sibling chapter.

(Find the table tent with your state to sit with your group in the main conference room.)

For those from states without a sibling chapter, meeting in Room 23 with SLN's Chapter Development leaders to learn more about how to start a chapter in your state.

**11:30 a.m. Closing Session and Open Mic****12:00 p.m. Conference Concludes**

*Thank you to our  
2017 SLN Conference Committee  
for all of their work to bring us all together!*

**After the conference:**

**12:30 p.m. – 2:30 p.m. CT Chapter Meeting** (CT siblings and SLN Board members are meeting to develop the CT sibling chapter over lunch)

**2:00 – 4:00 pm SLN Board Meeting**

## PRESENTERS

- ❖ Katie Arnold - [katie.arnold@siblingleadership.org](mailto:katie.arnold@siblingleadership.org)
- ❖ Carol Blessing - [cjb39@cornell.edu](mailto:cjb39@cornell.edu)
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### **FUN FACTS ABOUT THE SLN**

- The SLN has over 5,000 members across the country.
- There are currently 25 sibling chapters in states with the vision that every state will have an SLN chapter in the future.
- 5 Committees of the SLN are ways for people to get involved.
- Joining the SLN is free and easy—just sign up at [www.siblingleadership.org](http://www.siblingleadership.org)

## **KEYNOTE SPEAKERS**



### **Brian Donovan**

Brian has been a professional actor for more than 25 years in film, television, and radio. He has worked on-screen with such luminaries as Jim Belushi, Jim Carrey, and Angelina Jolie. He has been the voice of countless animated heroes. In addition, Brian has been the Executive Director of the Los Angeles Repertory Theater since 1994, producing and directing more than 50 inner-city high school workshops and live shows. He is also the creator, writer, and producer of the Mighty Me Training Camp ([www.mightyme.com](http://www.mightyme.com)) a top ranking children's self-empowerment program streamed by Discover Education for more than five years. Brian currently lives in Los Angeles with his family and dog, Cosmo.

## The Martin Sisters

### Kimberley A. Martin

Since joining Newsday in November 2007, Kimberley A. Martin has covered everything from local news to high school sports to the Super Bowl. In 2011, she was named the National Association of Black Journalists' "Emerging Journalist of the Year" for her outstanding achievement and balanced coverage of the black community and society at large. Before coming to Newsday, she worked as a local sports reporter for The Record in Hackensack, N.J. Kimberley received her B.A. in Psychology and African American Studies from Wesleyan University in 2003 and her M.A. in Newspaper, Magazine & Online Journalism from Syracuse University in 2006. Prior to grad school, she worked at an investment firm in Midtown Manhattan.



### Melanie Martin



At the age of 7 1/2, Melanie Alexis Martin was officially diagnosed in 1993 as being on the autism spectrum. As a bright and independently active young lady -- and self-proclaimed "Daddy's Girl" -- she learned to draw with encouragement from her late father, Compton. After graduating at 21 from P.S. 233 in Queens, she became a seasoned traveler with YAI's Leisure Trax Program, which organizes day and

overnight trips for special-needs consumers. In addition to being in ANIBIC's Day Habilitation program for nearly 10 years, Melanie currently attends weekly piano classes, as well as art classes at the YAI Arts program in Manhattan. She hopes that someday she'll be able to sell her finished work at YAI-sponsored art galas. Melanie has many hobbies, including swimming, jewelry-making, dancing, blogging and traveling. She's visited many places, including Mexico, the Caribbean, and Florida. In an effort to give back to her community, she's volunteered at both the Seaside and Central Libraries, the pantry and warehouse departments at the Food Bank for New York City and the SNAP Senior Center in Queens. Every year, she and her family also come together as the "MellieBears Team" for YAI's Central Park Challenge, an event that aims to raise

awareness and money for individuals with disabilities. A Brooklyn native, Melanie now lives with her mother, Camille, in Far Rockaway, Queens.

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Chiu, Caya	Co-Chair of Research Committee
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Sapharas, Barb	Co-Chair of Network Development
Tanis, Shea	Colorado Chapter Representative

**SLN CHAPTER REPRESENTATIVES**

AL-Wynona Raby	MS-Katie Nelson
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