



Fall 2017

Issue 5

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# Sibling Matters

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## Sibling Survey: We Want to Hear from You!

The Sibling Committee has created a [survey](#) to get a better understanding of what you would like to read in *Sibling Matters* and to gauge interest in other sibling activities throughout the five boroughs. Please click [here](#) to take the survey.

*We are always accepting new story ideas and other information from our readers! Please send submissions, resources and story ideas from you or other siblings you know to [kate.isenberg@ahrcnyc.org](mailto:kate.isenberg@ahrcnyc.org) or 212-780-4496.*

## AHRC NYC Hires New Executive Director: Marco Damiani



We are pleased to inform you that the AHRC New York City Board of Directors has announced the hiring of its next Executive Director. It was with a great deal of excitement and confidence and after an exhaustive search spanning several months that the AHRC Board of Directors announced that Marco R. Damiani has been selected to fill this position commencing December, 2017.

Many of you may know Mr. Damiani who is a highly accomplished and well respected senior health and human services executive. His career reflects many years of progressive not-for-profit I/DD and government experience in the fields of healthcare, behavioral health, community based services and long-term care as an agency executive here in New York City. He currently serves as the Chief Executive Officer of Metro Community Health Centers, Inc.; is the

Chairman of the Alliance for Integrated Care of New York; a former YAI Executive Vice President and Senior Director of Clinical & Family Services; and former Assistant Executive Director for Residential and Family Support Services at United Cerebral Palsy of New York City, amongst many other positions of ever increasing responsibility and influence spanning the last thirty-five years.

Mr. Damiani serves on several Boards related to the field of intellectual and developmental disabilities and is currently the Chair of the influential Manhattan Developmental Disabilities Council. He has played a leadership role in the identification, development and acquisition and millions of dollars in grant funding from government and non-governmental funding sources. He is highly knowledgeable in policy and practice around managed care, value based payments and transformational supports. He is committed to professionals in our field and to the people we support and their families. All of which will, no doubt contribute to his success at AHRC New York City.

Mr. Damiani will assume his new position in early December 2017 as Gary Lind concludes his five years with the organization. Gary and Marco will be working together over the coming weeks to facilitate a smooth transition. It is our collective vision to always provide services and supports to people with intellectual and developmental disabilities and their families that are second to none. The team at AHRC New York City has shown time and again its commitment to excellence and a passion for the AHRC mission. We have every confidence that we will continue our forward momentum and assure a successful future for the organization and for those whom we are privileged to support.

We extend a warm welcome to Marco Damiani.

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## SAVE THE DATE: AHRC NYC to Host Family Education Workshop on the Sibling Experience

SIBLING EXPERIENCES: A WALK IN OUR SHOES

Annette Spallino, Caroline Luna, Lindsay Kennedy, Sibshop Parent

**Wednesday, November 29, 2017 from 6-8 pm** at AHRC's Main Office, Penthouse - 83 Maiden Lane New York, NY 10038



This workshop will help us, family members and professionals, to be more empathetic to the unique experiences siblings of people with I/DD face.

**Official Invitation and Registration Info to follow in coming weeks.**

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## New NYC Sibling Support Group

[SibsNY](#) is very excited to announce that its monthly adult support group is starting again! The group will meet the second Monday of every month from 6:30pm-8:00pm at [SNACK NYC](#) (Special Needs Activity Center for Kids and Adults) at 316 E 53rd Street, NY NY 10022.



The first meeting is coming soon, Monday, November 13th 2017. For more information, please contact Kristy Hartman at [amysbigsisiter427@gmail.com](mailto:amysbigsisiter427@gmail.com) or [SibsNewYork@gmail.com](mailto:SibsNewYork@gmail.com)

SibsNY is a volunteer organization dedicated to providing the siblings of individuals with intellectual, developmental and learning disabilities with information and support. Comprised of siblings and providers of sibling services throughout New York, sibsNY is committed to connecting siblings to each other and to the resources they need to help them and their siblings with disabilities live the most fulfilling lives possible. We are the New York State Chapter of the national [Sibling Leadership Network](#). We are also contributing to the new Sibling Resources Website, [SiblingResources.org](#)

Contact info: [Sibsnewyork@gmail.com](mailto:Sibsnewyork@gmail.com)

Facebook: [SibsNY Group](#)

Meetup.com: [SibsNY](#)

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## Sibling Leadership Network Conference of 2017

By Lindsay Hyland



On June 25th and June 26th of 2017, Siblings from across the country met up in Hartford, Connecticut for the 2017 [National Sibling Leadership Network Conference](#). Siblings had an opportunity to connect with other adult siblings of people with disabilities and those who care about siblings. They heard from national experts on the latest in sibling services and supports, learned about new research initiatives, and heard about sibling and disability advocacy efforts. Siblings had the opportunity to learn about resources, share stories, network and gain insight on sibling experiences. It was a particularly special conference as The Sibling Leadership Network celebrated its 10 year anniversary! For more information about the sibling leadership network and upcoming information about their next conference, please go to [www.siblingleadership.org](http://www.siblingleadership.org). The conference is held every two years and is usually in conjunction with AAIDD (American Association on Intellectual and Developmental Disabilities).

One particular moment that stood out was the sharing of the film, [Kelly's Hollywood](#). Honest and raw, Kelly's Hollywood tells the intimate story of an aspiring actor who brings his sister, born with Down Syndrome, out to Los Angeles to pursue her dream of becoming a Hollywood Diva. But, as her health begins to fail and she becomes increasingly jealous of her brother's fiancé, he is forced to confront his co-dependent sibling relationship and the threat it is posing to his engagement. Brian Donovan, the filmmaker and brother, was there to share this film and answer questions from the audience. You can find more information and times the film will be airing on HBO at <http://www.kellyshollywood.com/>

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## AUCD Video Series: Tuesdays with Liz

Every Tuesday, Liz Weintraub, an Advocacy Specialist at the [Association of University Centers on Disabilities](#) (AUCD), hosts a video interview with an expert in the disability field. The goal of the series is to make disability policy accessible to everyone.



In past episodes, Liz has interviewed influential guests such as Lee Page, Senior Associate Director of Advocacy at the Paralyzed Veterans of America, and Liz King of the Leadership Conference on Civil and Human Rights. To find past episodes and listen to the newest interviews, click [here](#) or subscribe to the [Tuesdays with Liz YouTube channel](#).

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# Personal Feature: My Dear Brother Kenny

By Richard Borecky



My dear brother Kenny lives in an AHRC group home, known as an IRA. It's a private house in an upscale section of Brooklyn. He also attends an AHRC day program. For many years, he went to sleep away camp upstate. Kenny has an outgoing personality and expresses himself well. Since both of our parents are now deceased, Kenny looks forward to seeing me. I visit him at his house about every 1-2 weeks. Some days, just the happy, excited look on his face when he sees me makes me want to melt.

It's touching and very heartwarming knowing that he loves having me visit. Since he doesn't shave himself, I shave him as well as a couple of his other friends at the house. My brother loves CD's, and music in general, so we often listen to CD's together. When the weather is warm and pleasant, I often take him outside in the neighborhood. There is an apple tree down the block from his house that he loves to admire. We also have a friend in the area, so I will take my brother to visit him. Kenny loves the holidays, especially Halloween and Christmas. And of course, his birthday, which is his own special holiday. He requests decorations from CVS or the 99 cent store. This year, I bought him a big pumpkin and well as decorations for his house for Halloween.

Most of all, Kenny has taught me patience, understanding, compassion, and tenderness, all human qualities that money can't buy. I'm happy and proud to be his brother and when I visit him, his friends make me feel special and like a celebrity. They want to shake my hand, hug me, follow me around, and make me feel special. It sure is very heartwarming and touching, for sure.

The staff and management at his house do an outstanding job, for little salary, I'm sure. I commend them any time I have the opportunity. The patience they have and the love, care, and attention they give to my brother and his friends is immeasurable, remarkable, and very admirable.

As I mentioned earlier in this article, our parents are now both deceased. So, this July I officially became Kenny's legal guardian. It's a long process and a court appearance in front of a judge is required, but it's all worth it knowing that my dear brother's life is in my hands, and not in the hands of a hospital, the government, or the legal system. After all, no one loves my brother and is concerned more about his well-being than I am. The guardianship process is done through the Surrogate's Court. The staff at the court is very helpful. I strongly suggest that it be done sooner rather than later.

In closing, I commend all people who have a disabled sibling. Please be proud that you were chosen among others to be the brother or sister of someone who really needs you and appreciates you. We all need to stick together, help each other, and support one another. I'm always very happy to share my life experience of growing up with my brother with other siblings, especially the younger ones who may have many questions and concerns.

With love,  
Richie

## Sibling Meet & Greet in Canton, NY

On Tuesday November 8, SibsNY in conjunction with Sibling Resources and the

Developmental Disabilities Planning Council (DDPC) and Cerebral Palsy Association of the North Country are inviting adult siblings of individuals with intellectual and developmental disabilities (I/DD) to a meet and greet at 3 Commerce Lane in Canton, NY.

This is an opportunity to learn about supports and information that are specific to the unique role that a sibling plays as well as to meet others who may share common concerns. The DDPC is also looking to establish a listening session concerning the issues of service delivery for people with I/DD in rural parts of New York.

Light refreshments will be served, and a reservation is required to attend. For reservations and questions, please contact Jim Williams, Home Service Director at the Cerebral Palsy Association of the North Country, at 315-379-8202 or [jim@cpnorthcountry.org](mailto:jim@cpnorthcountry.org).

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## Stay In-the-know with Siblingresources.org



What is [Siblingresources.org](http://Siblingresources.org)? Siblings are important. In fact, siblings often have the longest relationship of their lives with each other. Yet siblings are often overlooked and sometimes even forgotten. This website is a resource focused specifically on siblings of people with intellectual/developmental disabilities.

Become part of a growing network of adultsiblings of people with intellectual/developmental disabilities and take advantage of up-to-date information, resources and training opportunities about issues impacting siblings every day! Register for free at [www.siblingresources.org](http://www.siblingresources.org) now!

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## Get More Involved!

- **Become a Member of AHRC New York City**

AHRC New York City relies on members support to help fund services, advocate for those in need and impact legislative policy. Become a Member of AHRC NYC today and add your voice to the many who share in your concern for people with developmental disabilities.

For more information or to become a member, call 212-780-2748 or email [membership@ahrcnyc.org](mailto:membership@ahrcnyc.org). You can also visit our [website](#).

- **Join the AHRC NYC Sibling Committee**

Help AHRC NYC come up with new and innovative ways to keep siblings involved and informed! If you're interested, please contact Kate Isenberg at [kate.isenberg@ahrcnyc.org](mailto:kate.isenberg@ahrcnyc.org)

- **Donate to the Jack & Helen Gorelick Sibling Scholarship Fund**

Support siblings who are interested in the field of I/DD! Each year, the AHRC NYC Foundation gives scholarships to college-age siblings who are interested in pursuing careers in the field of disabilities. To donate to the Gorelick Scholarship, go to the [AHRC NYC Foundation Website](#), click on "Donate," and in the designation field, type "Gorelick Sibling Scholarship."

- **Join the SibsNY Meetup Group**

Join the [SibsNY Meetup](#) group today and get connected with other siblings of people with disabilities in the NYC area. Open for siblings of all ages, the group shares fun activities, social outings, and information and support to help siblings meet the challenges of having a sibling with a disability. The Meetup group is run by [SibsNY](#), a member of the national [Sibling Leadership Network](#).

AHRC New York City | 212-708-2500 | [stayintouch@ahrcnyc.org](mailto:stayintouch@ahrcnyc.org) | <http://www.ahrcnyc.org>

STAY CONNECTED:

