



# Sibling Matters

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**March 2017**

**Issue 3**

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*We are always excited and honored to receive feedback and submissions! 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. Thanks, and we can't wait to hear from you!*

## Brooklyn Meetup Planned for Siblings

Sibs NY and the AHRC Sibling Committee will be hosting a Meetup at [The Douglass Bar](#) in Brooklyn for siblings to socialize and make new connections on **March 23rd starting at 5:30pm**. The Douglass Bar is located at 149 4th Avenue Brooklyn, NY 11217.



For more information and to RSVP for the event, click [here](#) or go to the [SibsNY Meetup](#) website. Please RSVP if you plan to attend so the venue can plan, and feel free to share this with siblings that you know that might be interested!

## Website Launched to Connect Siblings across NY

Siblings of people with disabilities are important, and there is an exciting initiative in New York focused on siblings. The [New York State Developmental Disabilities Planning Council](#) (NYSDDPC) has funded a project to build a sibling website, led by the [Yang-Tan Institute on Employment and Disability](#) at Cornell University, in partnership with the [Sibling Leadership Network](#) (SLN) and [SibsNY](#), which includes the sibling committee of AHRCNYC.

The [website](#) is dedicated to issues concerning siblings of individuals with disabilities. It is a resource focused specifically on siblings of people with intellectual/developmental disabilities. Over time the website will develop to include resources, online learning, and networking opportunities!

Become part of a growing network of adult siblings of people with intellectual/developmental disabilities and take advantage of up-to-date information, resources and training opportunities about issues impacting siblings every day!

Join us at <http://siblingresources.org/>



### Register on the Website for the Following Events:

Date and Time	Event	Location
March 12, 2017 7pm - 8pm	Sibchat: Sibling Support and Advocacy	Online WebEx
May 10, 2017 7pm - 8pm	Sibchat: Navigating the System	Online WebEx

## AHRC Held Family Education Workshop on SibShops



In January, AHRC New York City hosted a family education workshop for families of people with intellectual and developmental disabilities and professionals. The workshop featured Sibling Services Coordinator Annette Spallino, Sibling Committee members Lindsay Hyland and Caroline Luna, and parent Lori Jacobs, who all spoke about important topics and new resources for siblings. They discussed information about [Sibshops](#) and the new Sibling Resources Website (featured above). To receive information about future AHRC NYC Family Education workshops, sign up for our mailing list on our [website](#).

## Save the Date: SLN National Conference!

The 2017 National Sibling Leadership Conference, hosted by the [Sibling Leadership Network](#), will be held this year in Hartford, CT on June 24-25. The conference is open to adult siblings of people with disabilities, people with disabilities, parents and other family members, professionals in the I/DD field, and sibling supporters. Click [here](#) to register and to get updates on the event as they come!

## Personal Feature

*The next piece was submitted by a member of AHRC's Sibling Committee.*

### Direct Support Professionals Matter

By: Lindsay Hyland

My name is Lindsay Hyland and my sister, Julia, lives in an AHRC residence on Staten Island. She is unable to take care of herself independently and her basic living needs must be met by the individuals working in her house. This is not an easy job. Julia is able to communicate if she is hungry, or cold, or needs the bathroom, but she is unable to communicate other basic needs such as when she is sick, or has other problems. She needs help showering and getting dressed and needs support choosing food and drinks. To understand what Julia wants and needs requires getting to know her and her unique way of communicating.

One such person who goes above and beyond in getting to know Julia is Kelly Anderson, a staff member at the residence. The moment I met Kelly, I knew Julia would bond with her quickly. She is a lovely woman, who has an innate passion for supporting the lives of

individuals with disabilities and their families. She has gotten to know my sister Julia over the years and I'm honored to write that she has grown to love my sister like her own family member. She encourages Julia to try new things and supports Julia in community activities and outings. Kelly is a calming influence on Julia and whenever Julia and Kelly are together you can tell that Julia enjoys her company and feels safe and happy around her.

One particular day that will always stand out to me is my wedding day. As Julia needs a lot of care and support, I was worried that she might not be able to take part in my wedding day as all my family members were going to be very busy, and there might not be anyone who could assist Julia throughout the day. I wanted Julia to be a part of my wedding but I knew she needed someone to support her. Kelly took on this role and I will always be grateful for her for doing that. She traveled with Julia into the city and took care of her needs throughout the day. It would not have been as special of a day if Julia were not there so I will always be grateful to Kelly for being there.

It is not easy to have your most vulnerable family member live in a community residence. We have always wanted Julia to live as independent of a life as she could. There is not a day that goes by that I don't worry about Julia's well-being and safety. But, every time I arrive at Julia's house, she is always very content and is always learning something new or taking part in a new activity. Julia is very happy living in her home, which is a true testament to the hard work Kelly, and the rest of the staff does for her. Not only does Kelly take care of Julia's basic needs, she encourages Julia to step out of her comfort zone and try new things. It is so comforting to know that there are individuals in this world that go above and beyond in supporting your family members as though they are their own.



*Photographs of Lindsay and Julia taken by [Suzanne Fiore](#) earlier this year. Suzanne specializes in photographing people with disabilities and can be contacted through her [website](#). Lindsay noted that Suzanne "started to photograph Julia with my family without having her pose, and we started to realize that maybe 'posing' wasn't the way to go. So, Suzanne decided to follow me and Julia for the day. Not only did she get amazing photographs of Julia, she was also able to capture my relationship with her, which is not easy!"*

# Siblings, Advocate for Your Brothers & Sisters

## Join the #bFair2DirectCare Campaign!

A coalition of agencies that advocate and provide services for people with disabilities across New York State have joined together to demand higher wages for their Direct Support Professionals (DSP's). The #bFair2DirectCare campaign was started last year when New York State approved an increase in the statewide minimum wage to \$15 per hour, to be phased in over the next three years. It did not, however, provide needed funding in the budget for agencies like AHRC NYC to afford the pay increase. Additionally, DSP salaries were not provided with an adequate raise, meaning many employees in the field of disabilities services will soon be earning the same as others in less-demanding and less-skilled jobs outside of the human services field. In the governor's recently released 2017-18 budget, no further funds were provided to raise DSP salaries. Without immediate action from the governor or the legislature, there will be a crisis in staff recruitment and retention efforts for all service providers. The campaign has received [bipartisan support](#) from legislators who recognize the looming crisis and who have proposed allotting \$45 million to fund an increase of direct care pay across the state.



Join #bFair2DirectCare on [Facebook](#) and [Twitter](#). Click [here](#) to watch a video which further demonstrates the vital work provided by DSP's and why a pay raise is crucial to the futures of people with disabilities. You can also email [bfair2directcare@gmail.com](mailto:bfair2directcare@gmail.com) for more information.

## FDA Seeks Input from Families on Autism Treatments



The Food and Drug Administration (FDA) is seeking input from people affected by autism, including people with autism and their families, as they consider new treatments to address this disorder. The federal agency will host a [public meeting](#) on May 4th to discuss its impact on patients' daily lives, the types of treatments that matter most to patients, and the patients' perspectives on the adequacy of available therapies. It is hoping to learn what the unmet needs are and gain a better understanding of how families go about selecting treatments. The public meeting will be held in Silver Spring, MD, but will be available online via a live stream. In addition, the FDA will accept public comments on this issue through July 5th.

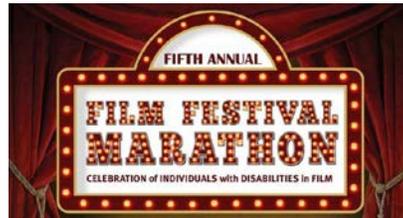
## Disability Film Festivals

### **Pace University: A Celebration of Individuals with Disabilities in Film**

Join Pace University and the Seidenberg School of Computer Science & Information Systems, in partnership with AHRC NYC and the [Reel Abilities Film Festival](#), for the fifth annual [film festival](#) marathon, featuring short films about autonomy and empowerment of people with disabilities.

The festival will occur on **Thursday March 23rd** starting with a 5pm reception and panel discussion followed by film screenings from 6pm-9pm. The reception and screenings will be held at Pace University: 3 Spruce Street, Bianco Room B-level NY, NY 10038.

To RSVP, contact James Lawler: [lawlerj@aol.com](mailto:lawlerj@aol.com), 212-346-1013.



### **Sprout Film Festival: Taking Submissions**

Sprout Film Festival is a nationally touring film festival dedicated to showcasing the best films related to the field of intellectual and developmental disabilities that is currently accepting [submissions](#) for its 2017 tour!



For submission instructions and to learn more about the festival's tour stops and the mission of Sprout, visit [Sprout's website!](#)

### **SAVE THE DATE: The AHRC NYC 68th Annual Dinner**

*Please join us for the 68th Annual Dinner, held this year on*

*Saturday May 20th 2017 at 6:30pm*

*The Grand Hyatt NY, Grand Ballroom*

*Honoring*

*Senator Jeffrey D. Klein & NYSARC President, Laura Kennedy*

*More details are available on the [AHRC NYC Website](#). If you have questions or would like to purchase a ticket, please contact Donna Gifford, 212-780-*

*2713, [donna.gifford@ahrcnyc.org](mailto:donna.gifford@ahrcnyc.org)*

# Get More Involved!

- **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](#).

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

AHRC relies on members support to help fund services, advocate for those in need and impact legislative policy. Become a Member of AHRC New York City 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 <https://www.ahrcnyc.org/involved/membership/>

- **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 AHRC NYC Sibling Committee**

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

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