Meet Some Members of the Sibling Committee!

**Toni Agovino:** I am a sibling. My deceased sister, Elena, was three years older, severely disabled and was the absolute joy of my life. I have been a member of the AHRC NYC for over twenty-five years and have been on the Board of Directors since 2003. I am following in the footsteps of my dad, Alphonse Agovino, Sr., who served on the board for twenty-six years. He was President of the Board from 1999 – 2002. I am also continuing the tradition of my parents as a lifelong, tireless advocate for the developmentally disabled, even after Elena’s passing. Born and raised in the Bronx, I spent most of my career as an administrator, working mainly in publishing and finance. I am now working in administration in the energy field, and I am also studying for a degree in business at SUNY.

**Richard Borecky:** I’m a sibling of my dear brother Kenny. My brother lives in an AHRC IRA in Brooklyn. The staff does a wonderful job caring for my brother and his friends, and I visit often. Kenny loves music CD's, snow, Chinese food, AHRC camp, and holidays. I work as Business Manager at a private high school in Brooklyn, responsible for the financial aspect of the school. I’m also a licensed US Coast Guard captain and love boating, navigation, the nautical environment, and the natural world.

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**Words from Nancy Petrino, Sibling Committee Chair**

Welcome to the first issue of “Sibling Matters”: A newsletter developed by the Sibling Committee of AHRC NYC for Siblings of someone with an intellectual or developmental disability. The Sibling Committee holds a special significance for me. My first introduction to AHRC NYC was through what was then the Sibling support group. When we learned that my mother was terminally ill, I realized that I was going to have to care for and advocate for my sister sooner rather than later. I felt overwhelmed and not sure what to do first. AHRC was like a port in a storm for me. I could talk with other siblings, get information and learn about different programs and services. I’m sure there are others out there with similar stories.

As the new Chairperson of the Sibling Committee, I see Sibling Matters and the Committee as a touch point and a source of information for Siblings whether they are already caring and advocating for their brothers and sisters or are growing into the role. We want to be a resource for you and provide opportunities for Siblings to connect with each other, express concerns and celebrate accomplishments with others who have gone through or are going through similar experiences. We will also connect with other Sibling groups to share information and even some get-togethers.

We are excited about starting this newsletter and we want it to be yours as well. We do want to hear from you about what topics you would like to discuss, hear more about and what questions you have. So please contact our Editor, Kate Isenberg, at kate.isenberg@ahrcnyc.org or 212-780-4496 to submit questions, suggestions or ideas for articles at any time. We are also looking for new committee members, so if you would like to help us in our efforts, please contact us at the above address as well.

-Nancy Petrino, Chair of the Sibling Committee at AHRC New York City
Fritz Charles: My name is Fritz Charles and I am a native of Queens, New York, where my family still resides. I am currently married and work as a Senior Manager at the National Basketball Association. I am the oldest child of 3, and I am 2 years older than my autistic sibling, Brian. My childhood was marked by the presence of my brother and his disability. Being nonverbal, I had to speak for him and learned that I was responsible for him from an early age. As he turned 30 this year, I reflect on the huge impact he has had on my life and the life of my family. He has always been a driving force for me as I knew that settling was not an option given that I was blessed with full capabilities to accomplish anything I put my mind to.

Lindsay Hyland: I am a middle school math teacher who joined the AHRC Sibling Committee a little less than ten years ago with the intent to learn how to become a better advocate for my sister, Julia, who is developmentally disabled and lives in a community residence run by AHRC on Staten Island. While on the committee, I have met siblings across the city and nation who share in the need to not only advocate for better resources for their disabled siblings, but also for siblings themselves, who often times become caretakers or guardians and need support finding resources. While on the AHRC Sibling Committee, I became the NY State Representative for the Sibling Leadership Network, which is a national network created to provide siblings of individuals with disabilities the information, support, and tools to advocate with their brothers and sisters and to promote the issues import to them and their entire families. You can learn how to get involved in the Sibling Leadership Network and its New York Chapter, SibsNY, in the article below about National Sibling Day.

Caroline Luna: I am a sibling. My sister Buffy, who is four years older, lives in an AHRC group home in Brooklyn. Buffy is my best friend and the reason that I am teaching today. My parents were active members of AHRC and life-long advocates for the developmentally disabled. I am trying to put into action the many things my parents have taught me. I have been a pre-school special education teacher for the past 16 years. I also work as a co-facilitator in AHRC’s Sibshop program and love the connections I have made with my sibs!

Nancy Petrino: My sister has been living in an AHRC Residence for the past 7 years and attends an AHRC day program. Previously, she had lived with our parents for most of her life. After our Mom passed away, she moved to a group home near where they were living in Florida. It was a long road getting her up to NY, but she is much happier here, and so are we. Our other sister, Liz, and I are thankful to have her closer so that we can see each other more often. We can be more involved in her life and she can be a part of family events and get-togethers. My sister never ceases to amaze me. She has an incredible memory and will often bring up some family memory that we had long forgot. She knows what she wants and is not afraid to say it, and she is also very considerate and compassionate, all qualities that I admire. I am also a member of the Board of Directors of AHRC NYC and a member of the Board of Governors of NYSARC. My career has been in advertising and marketing. I currently work in the media department of a large NY advertising agency as a Broadcast Account Manager.

Nilsa Santiago: I am the proud big sister and legal guardian of Nelson and Gilberto, two terrific and handsome gentlemen who are developmentally delayed and autistic. Nelson and Gilberto live in their home which was converted into an AHRC IRA after the last of their parents passed away in 2004. Nelson and Gilberto lead rich, very active and fulfilled lives and are the dapper toast of the town wherever they go. For my part, I was born and reared in Manhattan. I am a lawyer who practiced law for many years and am now a law professor. I have been an AHRC Board Member since the fall of 2007, but for many years before that I was very active in AHRC activities including the sibling support group and the Sibling Committee. My dad and I became lifelong members of AHRC in the 1990’s. In addition to my service on the AHRC board, I actively volunteer my time to several charitable, artistic and religious entities.

Did you know…?

AHRC New York City began one of the first sibling programs in the country back in the 1980’s. In the late 1980’s and 1990’s AHRC New York City sponsored several sibling conferences where siblings from the Tri-State Area gathered to talk about what it was like to grow up with a sister or brother with a developmental disability and the shared issues that siblings face. Today, AHRC New York City continues to run sibling programing in the form of Sibshops for younger siblings.

Several siblings are also members of the AHRC New York City Board of Directors where they advocate for their sisters and brothers with disabilities and give their perspective on subject matter being explored by the Board.
AHRC SibShops & Online Sibling Support

For more than 20 years, AHRC New York City has been supporting siblings of individuals with intellectual or developmental disabilities by offering Sibshops during the calendar year. Sibshops can best be described as opportunities for brothers and sisters of people with I/DD between the ages of 5-13 to obtain peer support and education in a recreational context with a kids-eye view. Sibshops can also heighten awareness that siblings are an important and necessary part of the equation when it comes to supporting people and families with special needs. As one parent once described it, “Sibshops are like a fun day at school spiced with confession, day-long sessions where siblings of kids with special needs can speak honestly about how their sibling makes them feel.”

Sibshops at AHRC NYC meet nine times during the calendar year, and often end with weekend camping trips to AHRC’s Camp Anne in upstate New York. AHRC NYC is committed to the well-being of siblings, who are the family members most likely to have the longest-lasting relationship with the person who has special needs. For further information contact Annette Spallino, LCSW at 212 780-2592 or log on to ahrcnyc.org to get information about upcoming AHRC NYC Sibshops. If you are interested in learning more about what is going on in online sibling communities for all ages, you may go to siblingsupport.org.

Personal Feature: Grief through a Sibling’s Eyes

By Caroline Luna

There is no greater loss than the loss of a parent. I experienced that loss twice within four years. One minute we were chatting over tea, and the next they were gone. All I wanted to do was curl up in a ball and push away the world. However, as a sibling of a person with special needs I couldn’t do that. My sister Buffy is four years older than me and has been diagnosed with cognitive and intellectual disabilities. I had to think about my sister and her future. That constant reminder of my responsibility to care for and protect her is always present.

So how did I cope? Instead of focusing on myself, I pushed my grief deep inside and put my attention onto my sister. I reminded myself over and over that Buffy needed me. She needs my protection and it is my job to see to her happiness. Those are the thoughts I dealt with during this time of intense sorrow. They weighed heavily on my mind and heart. That was also where I was most comfortable: helping others. I do that well, and it comes easy for me. It is taking time for myself and my own needs that I struggle with.

However, with time and through loving reminders from my husband, other family members, and close friends I re-set my priorities. Slowly and with much self-examination I began to allow myself time to grieve. I reflected on all the good my parents taught me and all the many reasons I miss them. I did something I rarely do, I took time for me!

I am not alone in my experiences. Many siblings face similar challenges and feel overwhelmed by the responsibilities of caring for their siblings after such a great loss. Fortunately for me, Buffy’s living arrangements were taken care of. She has a wonderful home and a loving group of people caring for her. Buffy’s future is secure and I am forever grateful to my parents for that; however, that was not an easy journey. There were many twists and turns along the road to guardianship. Papers to file that were missing and changes to be made establishing myself and my husband as primary guardians.

Feelings of guilt are a constant battle for me. I question whether I am doing enough and whether Buffy has what she needs to be happy. I ponder over my advocacy role. Can I ever be the advocate that my parents were? Will I be able to successfully walk in their shoes? Would my parents be pleased with my role in Buffy’s life or should I do more? These are questions I find myself thinking about often. It is at these times that I must remind myself that all I can do and give is my best. I’ve realized that no one can expect more of me than that!

Grief, though hard and never completely gone from our lives, can be managed. I wage a daily battle against these feelings of sorrow and guilt. Siblings need extra love and support during these times. They find them through the connections they make with other siblings who share their unique experiences and emotions. It is with this loving support that we are able to move forward and find happiness in new experiences. I continue to grieve each day for my parents but I find joy in memories of happy times spent together. I am confident that my parents would be proud of the advocate I have become and very pleased with the lives all three of their children are living!
The Gorelick Scholarship for Siblings of People with Disabilities

Do you know of a brother or sister of a person with I/DD who is in school studying an area related to I/DD? If so, you or they may be eligible for the nineteenth annual Helen and Jack Gorelick Sibling Scholarship. To access the application, click on the link: 2016 Gorelick Scholarship Application.

Applications are due April 15, 2016. Final applicants will then be interviewed in April or May, and the award will be given at the AHRC Annual Meeting on June 6, 2016 in New York City! If you have any questions, you can call AHRC's main line at 212-780-2500 and ask to speak with Jesse Backe.

Upcoming Events

Sibling Leadership Network Celebrates National Sibling Day!

The National Sibling Leadership Network is proud to celebrate National Sibling Day on April 10th, 2016! This is a day to recognize and celebrate the important role that siblings play in caring for their brothers and sisters. The Network's New York and New Jersey Chapters, SibsNY and SibsNJ, are hosting a National Siblings Day Lincoln Tunnel Challenge, a 5K walk/run through the Lincoln Tunnel open to all paces and abilities. Proceeds will benefit the New Jersey Special Olympics. After the 5K, the celebration will continue with more fun nearby. Join the run’s MeetUp group to stay updated!

Siblings can join the National Sibling Leadership Network for free at www.siblingleadership.org. The New York Chapter, SibsNY, is a volunteer organization dedicated to providing the siblings of individuals with intellectual, developmental and learning disabilities with information and support, and it connects siblings to services, resources and events in the area. SibsNY has a support group that meets monthly in Manhattan where siblings come to talk about some of the issues they are facing as siblings. SibsNY also meets throughout the year at social events and advocacy events and conferences. All of these events can be found at Meetup.com under the group SibsNY. Or, you can also find SibsNY and The Sibling Leadership Network on Facebook and Twitter.
The Sprout Film Festival

Sprout, an organization devoted to engaging people with disabilities through creative and social experiences, will be hosting its 13th Annual Sprout Film Festival on May 30th and 31st this year. Please click here for more information about the film tour and festival. To find out more about the other services that Sprout offers, you can read through its online brochure.

University of South Florida Sibling Study

A doctoral student of social work at the University of South Florida is seeking study participants for research on the effects on siblings who become primary caregivers to and co-reside with their sibling with a developmental disability after transitioning from the parental home. Participation includes 1-2 phone interviews about your experience of the transition itself and after the transition. If you would like to participate, please email rglaeser@mail.usf.edu.

Note from the Editor: AHRC’s employees and our Sibling Committee want to do everything we can to ensure that this newsletter truly adds value to your life and your relationship with your sibling. We hope that Sibling Matters can become a platform for siblings at AHRC to connect with one another and form a supportive and sharing community. That in mind, I would love to receive submissions, resources and story ideas from you or other siblings you know. Please contact me with stories or suggestions at kate.isenberg@ahrcnyc.org or 212-780-4496. Thanks, and we can’t wait to hear from you!