

THE SIBLINK | January 2017

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SIBLING SURVEY

Your Opinion Counts!

Click [here](#) to help shape the JFGH Sibling Network to meet your needs and interests.

It only takes 5 minutes! (All responses are anonymous.)



RECAP

33rd Annual Gala

Hope those who were able to join us on November 1st for the 33rd Annual JFGH Gala had a great time. Wasn't Andy Grammer terrific? To view more photos from this fantastic event, visit our [Facebook album](#)! While you're there, don't forget to like our page to receive JFGH updates.



Sibling Discussion:

Exploring the Joys and Challenges of Being a Local JFGH Sibling

On December 15th, a group of JFGH siblings gathered to discuss "[Transitions & Finding Balance](#)," a personal account of what it is like to be a sibling of an individual with a disability penned by Dorrie Pilot, sister of JFGH resident Gillian (Gillie).

Dorrie, Gillie and their two sisters grew up mostly overseas in Asia and Europe, but Maryland was always their home base. Dorrie is a professional photographer who owns her own business with her husband. You may have seen her at a JFGH event taking pictures for us! Dorrie and her husband have two teenage daughters, and she is a stage three melanoma survivor.

The group's discussion was friendly and informal. In fact, we barely made it through introductions before the conversation was off and running. Dorrie shared her story while those around the table easily identified with common experiences and emotions. It was interesting to hear the shared commonalities and differences.

Being the brother or sister of an adult with a disability can be both a joy and a challenge. Below is an abbreviated summary of the evening's open and honest discussion. Of course, the comments below may not necessarily apply to all readers, as we all come from different families and experiences.

- "Like our parents before us, it is important that we, as siblings, support JFGH so it will be there for us and our siblings in the future."
- Healthy diets are important, however, in certain circumstances, being respectful of our sibling's food choices, even when not particularly healthy, is also important.
- Without an inkling of hesitation about love and deep devotion to their sibling, there was a nod to feelings of resentment for inherited burdens. "Our parents had us by choice and were there from the beginning. This was not necessarily the case for us as siblings. We were born into the family."
- Family dynamics change as parents age.
- Siblings have a wonderful opportunity to educate their children.
- Some shared their feelings about doctors suggesting that their parents "Put her away."
- Some siblings are part of a multi-sibling family, while others are "only-sibs."
- Husbands understood that their wives were siblings of someone with a disability and they were part of a package deal; spousal support is felt and appreciated.
- Sometimes a sibling becomes the "surrogate parent."
- It is not always convenient to be a guardian of a sibling; such as when your children are young and need you. You are pulled in many directions.
- Typical children grow up and become independent. A sibling with a disability may peak in their ability.

- Some siblings struggle when they consider a move out of the area.

COMING UP

JFGH Bruce K. Smith Sibling Network Educational Program

You will not want to miss our guest speaker **Dr. Jamell White**, a clinician who works with individuals with disabilities and their families, for a two-part series, **Sibling and Family Discussions**:



<p>PART I Identifying Your Role in Your JFGH Sibling's Life</p> <p>Date: Thursday, March 23, 2017</p> <p>Time: 6:30-8:30 p.m. EST</p> <p>Where: The Joy W. and S. Robert Cohen Building 1500 East Jefferson Street, Rockville, MD 20852</p> <p>Please RSVP to attend in person or online no later than Thursday, March 16th to BShapiro@jfg.org.</p>	<p>PART II Communicating Your Role with Family Members</p> <p>Date: Thursday, June 8, 2017</p> <p>Time: 6:30-8:30 p.m. EST</p> <p>Where: The Joy W. and S. Robert Cohen Building 1500 East Jefferson Street, Rockville, MD 20852</p> <p>Please RSVP to attend in person or online no later than Thursday, June 1st to BShapiro@jfg.org.</p>
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SIBLING SCRIBBLINGS

There Should Be A Secret Sign

By: Jill Zuckman, sister of JFGH resident Beth

Everywhere I go, I see families like mine.

Browsing for Hanukkah presents at Sullivan's Toy Store recently, I heard a loud voice talking with the cashier. She sounded just a little too exuberant, her words slightly slurred. As I approached, I saw a young adult woman with an ID around her neck buying a toy. Watching the scene from a few

steps away was her was her father, elegantly dressed in a camel-colored cashmere dress coat. He looked at me, smiled, and said something about age appropriate toys.

I smiled back, and I thought to myself that there should be a sign.

I have this vivid memory. I was in an aisle of a Giant grocery store. My sister, Beth, wanted something on one of the shelves. She was pointing and trying to grab for it. My parents said no. She began to shriek and cry, and soon she was on the floor, refusing to get up.



Beth, Jill and Michael Zuckman

It was a full-blown temper tantrum. Of course, people were looking. Kids were staring. It was embarrassing.

That scene played out many times in many places during our childhood.

For Beth, who was born with profound intellectual and physical disabilities, the frustration of not being able to speak or to clearly communicate what she wanted, often resulted in tears.

She was born with a cleft palate, signs of cerebral palsy and seizures. She didn't learn to walk until she was four-years-old. She never learned to talk, though she picked up a little sign language and has the best laugh ever. At the hospital where she was born, the doctor told my mother not to worry, that Beth would grow out of all this.

Not so much.

For me, having a little sister who couldn't talk and often lurched when she walked, regularly resulted in stares. As a kid, it was uncomfortable.

Today, Beth is 49 years old. She's calmer and cooler in situations when we are out and about.

But everywhere I go, I see families like mine. I see a little girl with Down Syndrome at the new Mexican joint near Logan Circle, eating fajitas with her mom and dad. I see an adult woman on the Acela, headed to Union Station from Baltimore, trying to explain to the conductor that she's just trying to get home, even though she doesn't have a ticket.



Michael, Beth and Jill Zuckman

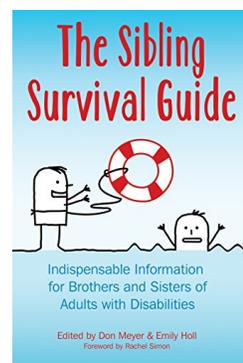
And I think to myself that there should be a secret sign. A look, a smile, a nod that says, I get it. I get you. Forget about the stares from people who don't know or understand.

If you have a sibling story you'd like to share, please email BShapiro@jfgh.org.

The Sibling Survival Guide: Indispensable Information for Brothers and Sisters of Adults With Disabilities

By: Don Meyer & Emily Holl

If you're a teen or adult sister or brother of someone with a disability, then this book is expressly for you. It offers implicit support by letting you know that you're not alone and offers tips on how to talk to your parents about plans for your sibling. And if you're already caring for your sib (or will do so soon) it also provides a crash course in guardianship, medical & legal issues, and government benefits.



FROM THE DESK OF...

Beth K. Shapiro, LCSW-C, JFGH Director of Social Work

The Bruce K. Smith Sibling Network celebrated its second anniversary at the end of last year! As the Network continues to grow, our primary goal remains: to connect JFGH siblings to each other and to JFGH through SIBLink, educational programs and events. For those of you located out of the area, we have not forgotten you! We aim to make it easy for you to be involved. Plans are in the works to incorporate a virtual element into our educational programs so that all JFGH siblings are able to participate. Also, we have just opened a new, private [Facebook group](#) to help you connect with each other. Please join! We hope you are as excited as we are to continue this journey together.



In order to grow this network, we need to know more about YOU; where you live, your age, a little about your sibling relationship, etc. To help, we have developed a [brief survey](#), also featured at the beginning of this newsletter. So far we have only received 11 responses. This is my plea to you to give us 3-5 minutes of your time to complete the survey. I also understand that some of you may not have received the survey, so here is your chance to have your voice heard! Your individual responses will be confidential. I look forward to sharing the consolidated results with you in a future newsletter.

I would really love to hear from you. Please feel free to send me an email or call me with your ideas, suggestions and concerns at BShapiro@jfg.org or call 240.283.6018.

Sincerely,

Beth

THE SIBLINK

A publication of the Bruce K. Smith Sibling Network



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