

THE SIBLINK | July 2017

[FROM THE DESK OF...](#)

[RECAP](#)

[COMING UP](#)

[SIBLING SCRIBBLINGS](#)

[SIB RESOURCES](#)

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

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Are you loving this sunny summer weather? It is a great time to get outside and explore! Thank you to each of the 75 people who did just that and joined us for the annual Bruce K. Smith Sibling Network Brunch and Boat Ride. I loved seeing all of your [smiling faces](#) as you enjoyed quality time with your siblings and families on the Georgetown pier. This is one of my favorite events because it encourages all of us to connect with each other and laugh along the way. This event would not be possible without the generosity of Nick Cibel, the gracious underwriter of the event. Thanks, Nick!



We have more engaging events in the works and hope you will join us! As always, I value your input and would 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 240.283.6018. Also, I urge you to take our brief, three minute [demographic survey](#) so that we can better support you.

Sincerely,

Beth

RECAP

Sibling Discussion Part II: Communicating Your Role with Family

On June 8 your JFGH Bruce K. Smith Sibling Network held the second of a two-part educational series, Discussing the Care of your Sibling with a Disability with your Family. At our first meeting in March, we focused on identifying sibling roles in JFGH residents' lives. Building upon that discussion, in June we talked about communicating this role with family

members. Dr. Jamell White, the Director of Special Needs and Deaf Services at the Jewish Social Service Agency (JSSA), reprised her role as guest speaker at this event, and we hosted an engaged group of siblings joined in person at the JFGH administrative office in Rockville and more siblings joined us from afar via our [private Facebook group](#).



Dr. White brought with her a handout that we used as a base for our discussion. It included five questions:

1. Who should be "at the table" as part of the conversation?
2. What is the "landscape" of those relationships?
3. How should the conversation happen? (face-to-face, phone, email)
4. When is a good time to have the conversation?
5. What do you want your role to be in your sibling's life?

At first the conversation centered on the fact that this topic is often overlooked and approaching parents and other family members can be challenging. Important to note is that this is not a one-time conversation, but rather an ongoing discussion that requires care and consideration from all parties. Some siblings are able and willing to take an active role in their JFGH resident's life, while others may not. We each come from different types of family relationships and have different personalities making our ability to have this conversation difficult for some. Siblings need to consider what level of involvement they want to or can have. The effort we can put in now may change over time as siblings' lives change. In fact, a sibling's role may change throughout the course of the discussions.

When considering who should be at the table for this conversation, some siblings said they preferred a sibling-only discussion, while others would like the JFGH resident, spouses, adult children or even JFGH staff or social worker present.

Part of this conversation revolved around a question: "Did you find out about your role in advance or was it day by day?" This often depends on the individual situation. For some siblings they are brought up knowing they will be the caregiver, others are "protected" by their parents who feel badly about a child's potential future responsibility. Others are suddenly put in the situation of caring for their JFGH sibling due to the illness of a parent or other change in dynamic.

Conversations about one's role can bring up sidelined family dynamics. One participant commented that for some, it may need to be separate conversations. There is the sibling/parent conversation, the sibling/sibling or any number of other combinations. There is many minutia that family members may not be prepared for. Research on such issues currently seems to reference the legal aspects, but there is little if any, about the conversation itself.

At this point in the discussion the question was asked why parents aren't talking to their other adult children about what they want in terms of future roles. Sometimes parents and siblings are not ready at the same time to have the conversation. Parents may not be ready to "let go." Some parents believe that no one will take care of their child as well as they can. Older parents are from a different generation that often hid their disabled child from society, making it a challenge for them to consider someone else, even another family member, taking on their role. Older siblings may want to consider who will take their role in the future.

Unfortunately, due to some technical difficulties we were unable to post the recording of the discussion. We look forward to hosting many of you at our next sibling discussion.

COMING UP

Alan Silverberg Fun Day

Join us! Each year the Silverberg family sponsors a day of outdoor summer fun for JFGH residents, and we invite you to bring your families, too.



This year's outing will feature a performance by two talented dogs, a viewing of Lego Batman once the sun sets at the park, and more! What better way is there to spend a day with your JFGH sibling?



When: Thursday, August 17, 2017, at 5:30-

9pm.

Where: Cabin John Group Picnic Area (7701 Tuckerman Lane, Potomac, MD)

RSVP to Shaunna Pickett at spickett@jfg.org, and find details [here](#).
See you there!



SIBLING SCRIBBLINGS

Being Susie's Brother

By: Joe Jolles, brother of JFGH resident Susie

Growing up with four siblings can be challenging for anyone, but for our family, it is and was our normal. Even though Susie has lived away from home since an early age, we still grew up together. Our parents never spoke down to Susie, so we didn't either. Our parents never favored her, so we never felt left out. Our parents treated us all the same, which we value as adults. Because of how our parents raised us and the supports they provided, I have never felt overwhelmed by taking responsibility for Susie or jealous of any extra attention she may have received. In fact, Susie herself would give you all the attention you needed, if you took the time to talk to or play with her.



Joe and Susie Jolles

I have many fond memories of our childhood, and what I admire most is Susie's ability to stand up for herself. There were times when people made fun of her, but I always considered that their problem-not Susie's or mine. I remember one time Susie and I went to the neighborhood pool and a lifeguard was standing on the diving board, making fun of her. Without batting an eyelash, Susie approached her and asked, "Oh, are you making fun of

me?" The lifeguard looked ashamed of herself, and one could only feel sorry for her-not for Susie.

At a different time we were at the Montgomery Mall and Susie threw a rare tantrum because she wanted a diet soda, and I wouldn't buy it for her. There, 10 people circled around us, wondering what was going on. I simply said, "Susie, you can scream as loud as you want but I'm not buying that diet soda because it's bad for you. You can get this other drink instead," pointing to a better option. She got very quiet and asked "Are you mad at me?" I said, "I think you are too grown up to throw tantrums," and she said she was sorry and never did it again.

When I was a teenager, I saw Ernest Angley on TV and he promised he could "heal"anybody if they come to his large-scale prayer meeting at Constitution Hall. Given my young age, I thought nothing ventured nothing gained, and maybe he really could heal Susie's brain damage from meningitis as an infant. We went, but they wouldn't let us in. Some very sincere people offered to pray for her outside the Hall, and before Susie and I knew, it a crowd of about eight very sincere and enthusiastic people were praying and rubbing Susie's head, yelling, "Lord! Recreate the Brain! Lord recreate the brain! Lord recreate the brain!" It happened so fast I was a bit shocked, but when I looked at Susie she was grinning from ear to ear, just basking in the attention and sensation of having her head rubbed.



Charlie, Hope, Susie, Joe and cousin Jody

Needless to say, growing up with Susie was always fun and still is. And what an adventure! Lastly, I know it will be an adjustment for me and my siblings to take on more responsibility in the future, but perhaps because there are a bunch of us and perhaps because we love her so much, I can't envision it as burdensome. My mom has already written a book on Susie's care, which is a great start! I honestly can only envision the future with Susie as a joyful responsibility shared with me and her other lucky siblings! We love you Susie!!



Joe and Susie Jolles

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

SIB RESOURCES

Caregiver College 2017



Arden Courts is teaming up with Holy Cross Health to host a series of events, Caregiver College 2017, geared to help caregivers prepare for assistance that seniors may need. Discussions include:

Hospitalization WILL Happen: Are You Ready? Saturday, July 29th; and
Ask the Experts: Panel Discussion Saturday, August 12th.

Each is scheduled to begin at 10:00 am and will be held at Cedar Lane Unitarian Universalist Church (9601 Cedar Lane, Bethesda, MD 20814). RSVP to 301.493.7881 or kensington@arden-courts.com.

Hot Weather Safety



The National Institutes of Health (NIH) recently released a fact sheet on keeping safe in the hot, summer weather. You can find their tips [here](#).

Jewish Social Services Agency



JSSA provides health and social supports to more than 31,000 people ranging from youth to seniors throughout the greater Washington metropolitan area. JSSA also employs a team of specially trained clinicians who work with individuals with disabilities to ensure strong mental health, prepare for employment and participate in the community. To learn more about their invaluable services, [click here](#).



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