

THE SIBLINK | April 2017

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

[JOIN US ON FACEBOOK](#)

[RECAP](#)

[COMING UP](#)

[SIBLING SCRIBBLINGS](#)

[SIB RESOURCES](#)

FROM THE DESK OF...

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

Chag Pesach Sameach (happy Passover), happy Easter and happy spring everyone!

In addition to all of the fun celebrations this time of year, did you know that today is National Sibling Day? April 10 is annually spent as a day to honor your relationship with your sibling, and we would like to honor you. Your support is so greatly appreciated, even if gratitude is not always clearly expressed. Your commitment to your sibling is special, and your experiences are shared by few.

I want to personally thank the almost 40 JFGH siblings who have joined our private [JFGH Bruce K. Smith Sibling Facebook group](#). I hope you have found it to be a JFGH community resource that is open to thoughtful discussions and fostering meaningful connections. If you are on Facebook, please join us!

As always, I 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.

Sincerely,



Join us on Facebook!

Would you like a way to privately connect both with JFGH and other siblings, sharing experiences with the opportunity to learn from each other?



As you may have heard, we recently launched a private Facebook group for JFGH siblings to do just that. The posts made here are only seen by siblings (and a few select JFGH admin). They cannot be shared or otherwise distributed, so this is a safe place to talk about your experiences and receive insight from other siblings, as well. Request to join [here](#). Please note that only JFGH siblings will be approved. Hope to see you there!

RECAP

Sibling Discussion Part I: Identifying Your Role in Your JFGH Sibling's Life

On March 23, we hosted a discussion attended by local siblings, with participation from afar via livestream and conference call. Dr. Jamell White, from the Jewish Social Service Agency (JSSA) in Rockville, MD, co-facilitated the talk, and we'd like to thank her for sharing her expertise. Thank you also to the siblings who were able to join us. The recording is available on the private [JFGH sibling Facebook group](#), and it will be removed at the end of May. (Please excuse the dumsy beginning; this was our very first livestream!)



The lively discussion brought about many insightful comments. One sibling noted, "*There seems to be a gap between the time parents know they have to pass on information and the time when they actually do pass it on.*" This is likely a shared concern and a good discussion point.

Here are some interesting statistics Dr. White shared during the meeting from a 2012 [Easterseals sibling study](#):

- Brothers and sisters of a sibling with a disability said their experience has had a positive impact on their quality of life.
- 80 percent of siblings polled said they are very close with their disabled sibling.
- Sibling involvement in future planning was more likely to be centered around residential plans and less on making financial plans.
- Half of adult siblings of individuals with disabilities either planned to or became their brother or sister's primary caregiver.
- One out of three siblings polled expected to become their sibling's primary caregiver in the future.
- Siblings were twice as likely to report being involved in their disabled sibling's life, and three out of four said being their sibling's primary advocate felt like it was a full-time job.
- Thirty percent of siblings polled felt they did not get much physical or financial support.

Be sure to look to our [sibling Facebook group](#) for polls related to JFGH sibling's perspectives on

similar issues. In the meantime, please [click here](#) to complete our five minute sibling survey so we can learn more about you as a group.

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 the second installment of **Sibling Discussions**.



Part II: Communicating Your Role with Family Members

Date: Thursday, June 8, 2017

Time: 6:30-8:30 p.m. EDT

Where: The Joy W. and S. Robert Cohen Building
1500 East Jefferson Street, Rockville, MD 20852; and the [JFGH Bruce K. Smith Sibling Network Facebook group](#).

Please **RSVP** to attend in person or online no later than Monday, June 5, to bshapiro@jfg.org.

SIBLING SCRIBBLINGS

Everything I Need to Know... I Learned from My Brother

By: Lisa Cordell, sister of JFGH resident Jason

Many years ago, as a middle school class assignment, I wrote about what it was like having a sibling with disabilities. Although I am not one to keep things from my childhood, I have kept a copy for more than thirty years, and in recently re-reading it, I was struck by how much has changed and yet how much has stayed the same. What struck me most is

everything that I need to know as an adult (and parent), I learned from having a sibling with disabilities.

For a while, I was an only child and grandchild -- the center of my parents' and grandparents' universe. In 1975, Jason was born, and by all accounts, was a healthy baby. While incredibly excited to have a sibling, I, like all other first-born children, now had to share my parents' and grandparents' love and attention with my brother. An adjustment for any child, my existence would be forever altered a short time later. On the day of my brother's bris (but before the actual ceremony), Jason suffered a brain hemorrhage, for reasons we still don't know today, that left him with extensive brain damage. Doctors felt Jason would progress very little. In terms of the most basic skills, their diagnosis was correct - even today, at 41 years old, he cannot walk, talk or do anything for himself. The doctors, with far less understanding then of how the brain works, also could not



Lisa Cordell and Jason
Chandler

have been more wrong about what he would be able to do. Jason knows how to charm (and get what he needs from) anyone he encounters; flirt with an attractive woman (and he is discerning); communicate his displeasure when not receiving the amount of attention he feels he should receive; and shower those of us he loves with affection.

As I wrote in that article so many years ago, while Jason changed my family's life forever in many ways, I can honestly say that the positive things that come from having him in my life far outweigh the challenges his disabilities pose. As I noted back then, and still is true today, *Jason's reason for being is to offer pure, unconditional love and joy, as well as inspire those around him to have the strength to keep going even during the most difficult and painful of times.* I have learned to have strength in the face of adversity -- to wake up each day as if the challenges from the day before are forgotten; to speak up for those who cannot do so for themselves; to persevere even when repeatedly being told "no," "it won't work," and/or "why bother;" to navigate sometimes endlessly challenging and frustrating situations using a calm voice and even keel when all I really want to do is scream; and to work towards making change rather than feeling sorry for myself and waiting (perhaps for an eternity) for someone else to fix something that is not working.

Ironically, life with Jason prepared me for life with my own children. Growing up with Jason, I learned compassion, flexibility, patience and understanding, which I must exercise daily with my daughter, Chandler, who also has special needs. Raised in Montgomery County, Maryland, my parents were among the first to fight for inclusion. Watching them work with the school system at a time when inclusion was just starting to happen to make sure Jason reached his fullest potential, I learned how to advocate so that Chandler gets what she needs to reach hers. I must share with you a powerful example of the benefit of an inclusive world. Some time ago, there was a student at my brother's high school -- Walt Whitman -- who volunteered in his class but, much more importantly, included Jason as part of her world - hanging with him at prom and even inviting him to her graduation party. After losing touch for many years, and unaware that she went on to pursue a career helping those with disabilities, that person, Rachael Wright, now works with Jason as his JFGH case worker. The positive experiences Rachael had in high school with Jason and his classmates seem to have inspired her career choice, and my family is so fortunate to have the happy coincidence of getting assigned to Rachael.



Lisa Cordell and Jason Chandler

Being a sibling of someone with disabilities also helps me every day in raising my other daughter, Samara, who does not have special needs per se. I say "per se," because I often feel that *"siblings of those with special needs also have special needs."* We belong to a rarified club that required us to grow up faster and have more maturity than our peers and often take on a lifelong commitment to helping our siblings once our parents can no longer do so. I have a unique bond with Samara, in that we both know the mixed emotions and often difficult realities that can come with living with someone who has special needs - sometimes feeling overshadowed by our siblings' needs, the discomfort that can come from living with someone who does not meet the expectations of a frequently cruel society, the patience and understanding that is needed to get through the days, to name a few.

But if not for growing up with Jason and watching my parents work tirelessly to make sure he has a full and rich life, I likely would not feel so driven to create change. Because of their example of having sat on boards to help steer the direction

of disability organizations our siblings participate in today, I have also been active in improving the lives of individuals with special needs and their families - from serving on the steering committee for my college-wide, 24-hour fundraiser for Special Olympics, chairing the Gala for my daughter's special needs school to co-founding the Inclusion and Accessibility Committee at my synagogue, Congregation B'nai Tzedek.



Chandler Family

While I would be lying if I were to suggest I did not wish that Jason could have been spared his issues, I am also so unbelievably grateful that being his sibling prepared me for adulthood and living a full and positive life.

To Jason, I love you and cherish my every day with you.

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

SIB RESOURCES

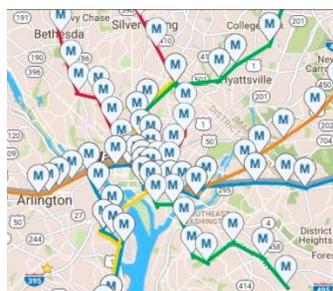
2017 National Sibling Leadership Network Conference



If you will be in or near the Hartford, CT, area, consider attending the 2017 National Sibling Leadership Network Conference June 24-25. The conference will feature national experts who will speak on the latest in sibling services and supports; an opportunity to learn about emerging initiatives; and most importantly, the

setting to connect with other siblings of people with disabilities. Visit the [conference website](#) for more information and to register.

A Guide to Transportation



A December 2016 Insurance Institute for Highway Safety report found that involvement in fatal crashes begins increasing among drivers ages 70 and above. This trend is attributed to increased medical complications. To better support both the elderly and individuals with disabilities, did you know that Montgomery County, MD, offers several means of transportation? Find out more about the different opportunities [here](#).

A Picture is Worth 1,000 Words



Maryland Developmental
Disabilities Council

empowerment • opportunity • inclusion

The Maryland Developmental Disabilities Council is welcoming photos that depict family togetherness for their fourth annual contest. Submissions will be accepted until April 28, and there are cash prizes. Find more information [here](#). We'd love to see a JFGH photo win!

THE SIBLINK

A publication of the Bruce K. Smith Sibling Network



Jewish Foundation for Group Homes
1500 East Jefferson Street
Rockville, MD 20852
P: 240.283.6000 | F: 301.576.4574

www.jfgh.org

Partner Agency of
The Jewish Federation
OF GREATER WASHINGTON

