



THE SIBLINK | October 2016

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One year ago, the sibling network was re-named the Bruce K. Smith Sibling Network in memory of our beloved resident, Bruce Smith.

With a goal of connecting siblings through engaging programs, useful resources and sibling stories, we introduced THE SIBLINK e-newsletter.

Thank you for reading!

RECAP



Disability Equal Voting Rights

With elections around the corner, we were pleased to host Carla Satinsky from the Montgomery County League of Women Voters and Nina Uzick from the Montgomery County Board of Elections on August 31st.

Carla and Nina shared great information which can be found in the "From The Desk of..." section below.

I hope to see you at our next event!

~ Beth



THE SIBLINK

A publication of the Bruce K. Smith Sibling Network

YOUR OPINION COUNTS!

Sibling Survey

As part of our commitment to JFGH siblings, the Jewish Foundation for Group Homes introduced the Bruce K. Smith Sibling Network in 2015. This Network was created to offer support, education and networking opportunities uniquely for you.



To date we have had a formal dedication, established a sibling committee that provides vision, presented quarterly educational speakers, hosted a sibling outing, and introduced SIBLINK, the network's quarterly e-newsletter. And we want to do so much more!

In order to provide a truly responsive sibling network we need to know more about you, the siblings of JFGH residents. **Thank you for taking 5 minutes to complete this survey by November 18, 2016.**

All responses will be kept private and confidential and the data you provide will guide us in developing targeted programs and facilitating meaningful connections. We look forward to sharing the data we collect in a future issue of SIBLINK.

COMING UP

Exploring the Joys & Challenges of Being a Local JFGH Sibling

Being the brother or sister of an adult with a disability can be both a joy and a challenge. Beth K. Shapiro, LCSW-C, Director of Social Work and JFGH sibling Dorrie Pilot, the author of the October 2016 Sibling Scribblings article below will be co-facilitating a lively discussion.

Date:

Thursday, December 15, 2016

Time:

6:30-8:30 pm

RSVP:

Please RSVP no later than Monday, December 5, 2016 to BShapiro@jfgh.org.

Where:

The Joy W. and S. Robert Cohen Building
1500 East Jefferson Street, Rockville, MD 20852



SIBLING SCRIBBLINGS

Transitions & Finding Balance

By: Dorrie Pilot, sister of JFGH resident Gillian (Gillie)

It's hard to believe it's been almost 20 years since I became guardian of my sister Gillian (Gillie). As the sibling of an individual with Down's syndrome, I inherently knew that one day I would become her caretaker, but I was completely under-prepared when the time came abruptly at the very young age of 26.

Transitioning from sister to guardian, for me came with a heavy price. The sadness of losing Gillie as my friend, and stepping into a more parental role with all of the responsibilities and frustrations that accompany caring for someone with a lifelong disability still persist, but as the years pass by, I am learning (still learning) to accept my new role in her life, and consciously try to practice that role with grace, understanding, and lots of humor.

Before our parents passed away, Gillie and I enjoyed a friendly sister relationship. I loved her like a protective older sister, and thoroughly enjoyed our carefree interactions. Like many siblings of disabled children, I was and still am her fiercest defender, quickly giving the evil eye to any stranger who may have snickered or stared at my kind and sweet baby sister. Hearing the "R" word would send me into a tizzy. I had her back, and she had mine. We had fun together, played in the park together every night, went shopping at the mall, giggled, and truly enjoyed each other's company.



Dorrie & Gillie

That all changed when our mother passed away suddenly one August evening, and I was instantly thrust into full blown caregiver mode at the age of 26. How would I care for my sister? Would we live together? How would I work and still care for her? How would I date someone and care for my sister at the same time? How would I learn how to handle her finances? Make medical decisions? How would I marry? Raise my own family? Those were a lot of heavy issues for a 26 year old to think about. There was no plan in place in our family for her care after my parents death, one of my few true regrets in life.

By the grace of God we were put in touch with a wonderful Special Needs attorney and my legal guardianship was put in place. I'm pretty sure that is when I truly became an adult. I learned what it meant to be fully responsible for another human being. It's also the time when our relationship transitioned from siblings, to more of a parent/child relationship. I became, in effect, her mother. And both of us resented it. Our relationship suffered. She was angry when I made decisions she disagreed with. I was angry that I had to make those decisions for her. We were suffocating each other.

Thank goodness we found JFGH.



It has taken 20 years of working on our relationship, and finding balance as a sibling and caregiver of a disabled adult, but today, Gillie is happy living independently at the Revitz House in the JFGH Apartment Program. Our relationship has transitioned once again to more of an adult child/parent relationship. Like many parents, whose children grow up, move away and become independent, I have learned to breathe and let go, with the help of some amazing counselors and JFGH staff, who I have learned to trust and appreciate with every fiber of my being. We work together as a team, to help Gillie be as independent as she can be.

With the support of the apartment program, I no longer feel overwhelmed. I am confident in my decisions. I married and had children of my own that I am able to care for. Gillie has lots of structure and supports in place. She and I have a respect for each other's roles now. She is happy, she is independent. She is safe. She is an unbelievable human being.

And I don't resent being her guardian, not for a second.

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

SIB RESOURCES

Building the Future, Now! Webinar

Building the Future, Now!, a collaboration between The Maryland Developmental Disabilities Council and The Arc Maryland, is presenting the following webinar to learn more about DDA Services and Employment First.

Employment First: New Opportunities, Dispelling Myths & Misconceptions
Thursday, November 10
12:00 - 1:15 p.m.

For more information and to register, [click here](#).

This session will provide insight into the principles behind Employment First, explain the Employment First initiative, provide a family perspective, and answer the question, "How do we help people with significant disabilities benefit from Employment First?"--followed by Q&A.

Presenters:

- Mat Rice, People on the Go Maryland
- Family member - TBD
- Rachel London, Maryland Developmental Disabilities Council
- Staci Jones, The Arc of Washington County

Nursing Home Regulation Changes

The Centers for Medicare & Medicaid Services (CMS) released revised nursing home regulations that depart dramatically from previous regulations, and will impact the lives and care of nursing home residents for years to come. As part of the new rule, nursing homes are now prohibited from including binding arbitration clauses in their admission agreements with residents. Prior to this change, nursing home residents were required upon admission to sign away their right to sue for neglect and abuse. "It

prevents nursing facilities from taking advantage of people on the front end and having them sign things when they're thinking about everything other than arbitration," said Justice in Aging attorney Eric Carlson in a [story about the new rule in the Epoch Times](#).

FROM THE DESK OF...

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

Thank you to those who were able to attend our program about Voting Rights on August 31st. Below is a summary of the history, voting tips and great resources that Carla Satinsky and Nina Uzick shared with us.

A Very Brief History

In the past, states severely limited individual's voting rights and the majority could not vote. To do so an individual had to be male, own land, Caucasian and Protestant. He had to also be able to pay a pole tax and pass a reading and comprehension test. The population could not vote. In fact, most of the people in the room for this program would have not have been allowed to vote during the early days of our country's voting history. President Lincoln was only interested in expanding the ballot to African Americans, not women. As I am sure you know, in 1920 women were given the right to vote. But many voting restrictions lasted until the 1960's. Only in 1972 did individuals under age 21 get the right to vote. The thinking was that if a man could be drafted and sent to war at age 18 they should be given voting rights.



There were many conventions about people with a disability when it came to voting rights. For example, it was assumed that if someone used a wheelchair, had Cerebral Palsy or had Autism they were not able to vote. In days gone by the thinking was if you could not use your legs, how could you possibly vote?

Individuals with Disabilities

Maryland is one of the most welcoming states in the country regarding voting rights. Voting machines are accessible and accommodations are made for anyone who would like to vote. Individuals can 'challenge' someone's ability to vote, and although this happens, it is rare in our area.

An individual who understands they have a choice and knows there is an election is welcome at the polls. The Board of Elections is not in the business of deciding who can and cannot vote. A person experiencing a dementia such as Alzheimer's disease, for example, may still have a good which candidate they want to cast their vote.

The Ballot

This fall, when we go to the polls, it is important to remember that we not only have the opportunity to vote for president and vice president, but we also have the opportunity to vote for those who will represent us in the Senate, House of Representatives, as judges, and on the Board of Education.

Things to Note

- Use the [voter look-up website](#) to find out if your polling place is accessible. If your polling place is not accessible, there will be a list of the reasons why. This may help you decide if the polling place is accessible for you.
- In Maryland it is illegal to be asked for proof of who you are.



- If a voter cannot manually fill out a paper ballot, which will be used this year, they can request a touch screen.

Resources

1. [League of Women Voters](#) are there to answer your questions:
 - Ask about voter assisted forums
 - Guardianship
2. [Voting Poll Accessibility](#)
3. [State Board of Elections](#)
4. 311 Access: Call 311 with a question regarding where to get information about any Montgomery County, MD service or program

If you have any questions, please email me at BShapiro@jfgh.org or call 240.283.6018.

Have a wonderful fall,

Beth

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