

THE SIBLINK | October 2015

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RECAP

Bruce K. Smith, our beloved resident, was supported by JFGH for nearly 25 years. After his passing, the Smith family made an extraordinarily generous gift in Bruce's memory in appreciation for the superior care JFGH provided.

In early September, family, friends, community members and JFGH siblings gathered for a memorable ceremony to officially re-name the Sibling Network, founded in 2003, **The Bruce K. Smith Sibling Network**. The Network is for JFGH residents and their siblings providing social, emotional and educational support through programs and events.

After the dedication ceremony, Beth Shapiro, LCSW-C, JFGH Director of Social Work, shared her vision for the program. Then the siblings were divided into small groups for an icebreaker that allowed them to introduce themselves and share brief information and insights about their JFGH sibling.

The Bruce K. Smith Sibling Network has four goals:

1. Provide social opportunities designed to support sibling relationships
2. Design meaningful opportunities for non-resident siblings to network and connect
3. Offer emotional support for non-resident siblings
4. Create educational opportunities unique for siblings of adults with developmental disabilities

In keeping these goals in mind, JFGH is pleased to introduce THE SIBLINK, a publication of the Bruce K. Smith Sibling Network. This quarterly newsletter--relevant to both local and out-of-town JFGH siblings--will include upcoming events of interest to JFGH siblings, information about other related activities, links to articles and research, JFGH updates and of course, photos!

In addition to THE SIBLINK, we will also offer a periodic speaker series and events where local siblings get to know each other in person. And, we are very excited for the development of an online forum for JFGH siblings to meet and discuss common topics of interest. This will be a mechanism for local and out-of-town siblings to participate, contribute and connect.



COMING UP

Growing up with my older sister Jennifer meant learning how to advocate with her at an early age, defining for ourselves what 'disability' means and breaking all sorts of cultural barriers. Being her sibling has allowed me to witness first-hand that anything is possible.

Our first speaker will be Carolyn Chen, Sibling Support Coordinator with the Maryland Developmental Disabilities Council, who will share her insights on Sibling Support & Advocacy on **Tuesday, December 1, 7:00-8:30 PM** at The Joy W. and S. Robert Cohen Building, 1500 East Jefferson Street, Rockville.

Please RSVP to Beth Shapiro, LCSW-W, Director of Social Work, at 240.283.6018 or BShapiro@jfqh.org.



Carolyn Chen

SIBLING SCRIBBLINGS

Virtues My Brother Taught Me

By: Patty Aycock, sister of JFGH resident, Bob Curran

My sweet brother just turned 57. It was our turn to host his birthday party. It was grand. The genuine highlight in his life is to be surrounded by his big, loving family. Pure Heaven. He's The Star. His party was highly anticipated indeed. This is a time of reflection, too.

As the fifth sibling, born in 1958, Bob has Down syndrome. At 65, I'm a big sister and a 20-year legal guardian. Always gregarious, my charming, happy, favorite brother is sadly now digressing with Alzheimer's confusion and memory loss. Yes, I wept at the news and the loss surely to come. But wait, his life has much to teach me, still.

Anticipating mortality brings introspection, self-examination. In that evolving emotional journey, I've realized now that without sweet Bob, I'd never have the chance to reach deep into my heart and mind, and find life's richest, most meaningful gift. That gift is making another, Bob, abundantly happy and knowing unconditional love. Not by saying, by doing. He arrived abundantly happy, as many people with Down syndrome do. He is well loved and so easy to love. Gentle Bob is always patient and kind. I hope to meet him where he is - at any given moment - every time.

Our family has the good genetic trait of lots of energy. Imagine the challenge of gearing down from our high energy to Bob's speed, and maintaining his pace, happily. That's patience. I've learned to listen to sweet Bob persevere, or repeat himself multiple times, and stutter, for a lifetime.



*Patty & husband Bob
with her brother Bob Curran*

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I wait patiently for him to get out each word, and that's okay. It's not my voice he hears, but my face he reads. That is patience I learned from him. We all need to be heard.

Kindness--I completely learned from sweet Bob. He's the kindest, most gentle one I know. Out of the blue long ago, it struck me that Bob is the epitome of kindness. Lacking malice or complicity, he is what a friend calls "having a pure heart". It took forever to fully comprehend "a pure heart". Now it feels transcendent - powerful, beautiful, loving. Can we have more of that from humanity? Just watch sweet Bob - his full smile can melt an iceberg.

The role of sister, advocate and chief cheerleader is one I want to do well. Wearing those hats brought the added virtues of fortitude, perseverance, and prudence-looking ahead to pre-plan for Bob's future. Time, hopefully, has added a sprinkling of wisdom and maybe some knowledge. Thanks, Bob, for the all the virtues you taught me. I am forever in your debt. Where and who would I be without you in my life? It's ironic, how people often say how lucky Bob is to have me as he sister. The truer fact is how lucky I am to have Bob as my brother.

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

SIB RESOURCES

Join JFGH as we show our support for siblings! This **Saturday, October 17**, MDSibs an organization that connects siblings of people with development disabilities will host a statewide conference for siblings and others interested in sibling issues. This conference is an opportunity to bring children and adult siblings of people with developmental disabilities, people with a disability, family members, service providers and professionals together.



To register, please email MDSibs at mdsibs@md-council.org or call 410.914.SIBS (7427).

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FROM THE DESK OF...

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

Don Meyer, Director of the Sibling Support Project, told me "If you want to ensure long term positive outcomes for people with developmental disabilities, invest in their brothers and sisters."

With the generous gift of the Smith Family, JFGH is now able to invest more than ever in our sibling network.

The network has formally kicked off with our first program and this newsletter thanks to committee members: Patty Aycock, Laura Cole, Ken Gilman, Harry Malech and Jonathan Sachs. Their insight as siblings along with their energy and time behind the scenes helps to make the Network a strong and valuable resource.

I look forward to meeting all JFGH siblings and offering engaging programs, educational resources and support. You can reach me at BShapiro@jfg.org or 240.283.6018 with your ideas as our JFGH sibling network flourishes.



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

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