This Q & A article is from BDSRA’s “Ask An Expert” Facebook Chat in the BDSRA Closed Facebook group for parents and caregivers.

\*Please note: the information contained in this document is intended to provide

basic guidance to Batten families, parents and caregivers.

It is not intended to be, nor is it, professional advice for individual children.

Parents and caregivers should consult the child’s physician and/or counselor regarding emotional or mental health concerns.

“All Things Siblings”

Adult siblings Adeline Heuchan and Brian O’Neill,

with Becky Hetteberg, MSW, LISW-S, BDSRA

February, 2015

**Q. What sorts of activities do siblings do at the BDSRA conference?**

A. So, the sibs like to plan outings that are memorable and exciting for all siblings! Every year there is a main sibling outing that pertains to the area the conference is located. For example, last year we all went to Shedd Aquarium because when people think Chicago, Shedd comes to mind!!

**Q. How do sibs get to the activities?**

A. Well, the SIBs coordinate with the BDSRA to get buses (since we have so many wonderful SIBs!) to take us to and from the different locations.

**Q. Do you know yet where SIBS going this year?**

A. Yes, we have a few awesome outings planned, including the St. Louis Children's Museum which was a huge hit last time (It has a couple story slide!!). Check out their web site: [www.magichouse.org](http://www.magichouse.org)

**Q. Are there "counseling" sessions for the sibs to talk about what they are feeling in their homes? As a mom I hear "it's not fair she doesn't have to do homework or chores etc".**

A. The sibs do attend sessions in which they can talk about feelings, how school is going, frustrations, their affected sibs, friends, home life, etc. These are closed sessions so the kids feel comfortable sharing with other siblings.

We also have a parent panel during the conference where parents get a chance to talk to the adult sibs and debrief on how to talk to their own children about things going on. Sessions are also a great thing for sibs because it "normalizes" the things that sibs face every day in an abnormal situation. They no longer feel that they are the only one going through something. They also are like "hey, you're getting counseling too?! I guess I'm not the only one..."

We also have a Sib-Parent Panel on the Saturday of the conference where parents can come and ask a group of adult sibs different types of questions. For example, “my child is acting out in a specific way, what should i do?” or “how can I help give my affected child’s sibling lead a 'normal' life? “When should I tell my affected child’s sibling what is going on?”

**Comment.** The Sib-parent panel is my favorite session each year. Very helpful! We are thankful for the sibs program; it’s amazing!

We have seen some parents decide not to bring their unaffected sibling to the conference because they are afraid of what they will see or hear. My best suggestion is generally to talk to the sib about what is going on (they realize more than you generally know) and allow them the chance to come to the conference.

We do not force them to talk about anything but we can talk about everything (the good and the bad) and if they feel that the sessions are too much and want to sit out on one, that is ok to! Sometimes parents wonder about what kinds of sessions are being held....or should my child even go to the morning sessions...or will the session be beneficial for my child to attend. Yes, Yes, and Yes!

One session that I always look forward to is the "Meet the Scientist" session. This is where some of the scientists and researchers come and answer questions that the kids have about the confusing science behind Batten. The scientists are really good about putting the language into layman terms for the siblings. The scientists also talk about new research that is going on in their labs.

**Q. I assume there will be a session for sibs that have recently lost their brother or sister? And are they grouped with the main sib group or are they separated**

A. Yes, we have a bereavement session, usually on Sunday, specifically for sibs who have lost a sibling. They are all grouped together so that siblings who have recently lost a sibling can talk with other siblings in the same boat, or ask questions to the older sibs.

**Q. What is your age range of sibs that join in on the activities?**

A. We have activities for siblings ranging from 6 years old and older.

**Q. Do sibs keep in touch throughout the year? My son is 12 years old and he hasn’t talked to anyone through the Sibs program outside of conference.**

A. I can honestly say that for me, as a sib, I did not reach out or contact any sibs until I was older. Each child is going to act and react differently. It may just take longer than you expect. The sibs program is very unique in that it is totally sibling planned and run. Sibs create a long-lasting support system with other sibs at the conference; they connect with people they can lean on, call upon, and text when they want to talk or hash things out. This was really important to me and I am always thankful to have these life-long friends.

**Q. What are some other resources for siblings?**

A. There are some online resources and links on the BDSRA web site: <http://bdsra.org/support-for-batten-siblings/>

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**BDSRA**. Our SIBS program is one of the few in the nation! And it’s all because of the incredible leadership of our adult sibs!