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 material is intended to provide basic information to Batten families and caregivers. It is not intended to be, nor is it, medical advice for individual children. Parents and caregivers should consult the patient’s physician prior to changing medication, medical treatment or daily activities.

“All Things Sibs”

Featured Experts:

Sibs Leaders: Adeline Heuchan, Jeni Montavon, Sara Thompson

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1. What Pittsburgh activities are you most excited about?
   1. I know I am very excited about the space in the conference rooms for this year! Super cool! We are so excited about the outings!! Science Center and the Natural History Museum, which we will be doing fun activities like a flashlight tour and laser tag.
2. Are there resources to have the Sibs stay connected during the year after a conference?
   1. One good way is Batten Blueprint (battenblueprint.com), which is a website for sibs to stay connected and watch videos from other sibs. We also have a Sibs Facebook page. Batten Blueprint is open to sibs of any age. Sibs can reach out to any of the sibs leaders at any time to get the password to access the site.
3. Did you have a lot of classmates ask questions about your sibling when you were in grade school?
   1. For me personally, no as my brother is 6 years younger than I am and he never got to interact with my classmates unless they came over. A select few went through the diagnosis process with us but outside of that, as I got older (end of high school beginning college) it became easier to explain about him to my peers.
   2. My sister was 5 years younger and when we were in grade school she wasn't diagnosed with Batten Disease, she was visually impaired she was not showing other symptoms.
   3. I did, my brother and I are only 2 years apart. The questions were usually about him being blind and very general questions. I did a presentation at one point in my school on Batten Disease to my peers so they would know. As far as wanting to make your unaffected sib not feel so different all the time, its shows how great of parents you all are! But being different makes us who we are and shapes our lives, if your sib ever needs to chat to another sib through the year please reach out to any Sibs leaders and we will help anyway we can.
4. What sort of topics do you cover in the conference sessions?
   1. We have a research session, age specific sessions, all age sessions, and a bereavement session. We also have a Sibs/Parent panel for parents to ask questions to a group of older sibs, this is a very popular session for the parents. In the sibs sessions we cover a broad range of topics and nothing is really off limits. We try to create an open, supportive environment for everyone. For the younger groups we discuss age appropriate topics. We strongly suggest that parents talk to their children about Batten Disease prior to the conference. We cannot filter sibs from discussing the prognosis and its best if they get this information from their parents.
5. What are the benefits for a sibling going to a conference?
   1. The friendships are lifelong, I also like keeping in touch with other parents. We are all in this together as one big family.
   2. There are so many benefits to going to conference. I know that for me, it is a group of people that essentially become family. You can talk to each other about anything or nothing with no judgement. And you get to spend time with people who go through everything you are going through and feel everything you feel about this disorder
6. Is there anything else about the conference sessions that you'd like parents to know?
   1. Having the "close" sessions allows SIBS to really feel comfortable and express their feelings knowing the information doesn't leave the room. We want the Sibs to feel they can be open and completely honest about how they are feeling. If parents are around the conversations are more guarded. We have better responses from sibs when they are surrounded by their peers.
   2. We also have the sessions split up in a specific way so that the SIBS can get as much out of conference as possible without being overwhelmed the entire weekend (allow for some de-compression and fun)
   3. We also have a bereaved session for SIBS whose affected sibling has passed to talk and remember their siblings.
   4. The conference is not all sessions we do lots of fun thing and go out on different outing every year!!!