

Stepping **FORWARD**

2020 Bloom Syndrome Conference



Webinar
Series

Session 3: Parenting a Child with Bloom Syndrome

JULY 8, 2020



Webinar Logistics

- This webinar will **NOT** be recorded.
- Please mute your microphone unless you are speaking.
- Unlike other webinars, feel free to chime in with questions or comments at any time – and we’re hoping everyone will participate! (If multiple people want to talk, we’ll use “Raise Hand” feature in chat box.)
- Zoom questions during the session? Use the Chat feature to request assistance from the person who is listed as “Tech Support” in the participant list.
- We will post a copy of the slides only on the BSA website.



Webinar Agenda

- Session objectives, Session topics– Leslie Ryan
- Introductions – Facilitators
- Breakout sessions & regroupings – Everyone
- Brainstorm session: what is the one thing you wish you had known? – Everyone
- Wrap-up – Leslie Ryan



Session Objectives

- Help build relationships between parent members of the Bloom Syndrome Association so that we may rely on each other in the future
- Better understand the issues that parents face and where the BSA might be able to support



Session Topics

- Talking with your child about Bloom syndrome
- Supporting your child's handling of social & emotional challenges, throughout the years
- Navigating differences between siblings
- Taking care of yourself
- Other topics? Use the chat feature to suggest.



Facilitator Introductions

- Jackie LaHaye
- Jim & Natalie Rogers
- Mary Beth & Wes Campbell
- Anne-Marie & Henri van den Hurk



Topic 1: Talking With Your Child About Bloom Syndrome

- Introductions: name, age of child(ren) - - list in Chat
- Questions for discussion:
 - For those parents (or persons with Bloom syndrome):
 - At what age did you first talk to your child about Bloom syndrome?
 - What went well?
 - What do you wish you had done differently?
 - Advice on age-appropriate language, topics?



Topic 2: Supporting Your Child's Handling of Social & Emotional Challenges

- Introductions: name, age of child(ren) - list in Chat
- Questions for discussion:
 - Did your child face/does your child face any social & emotional challenges? What are they? How do they change over the years?
 - Perspective from those with Bloom syndrome?
 - Any tips or advice?



Topic 3: Navigating Differences Between Siblings

- Introductions: name, age of child(ren) - list in Chat
- Questions for discussion:
 - How do you deal with what may be different rules for different siblings?
 - How do you think it affects your non-Bloom children?
 - Any tips or advice?

Topic 4: Taking Care of Yourself

- Introductions: name, age of child(ren) - - list in Chat
- Questions for discussion:
 - What are the hardest parts for you as parent?
 - Where do you need support? How do you get it?
 - Do you have any tips on how to take care of yourself, while also raising your child?



Brainstorm: What's One Thing You Wish You Had Known at Day One?

- Advice? Tips? Words of encouragement? Resources that exist (or should exist)?
- Write in the Chat!
- We'll compile on a slide and include it in the slide deck on the BSA website.

Our Collective “Day One” Advice!

- Don't stress about food intake and weight, especially during infancy.
- Trust your instincts!
- Not everything is as dark as it seems.
- Let your Blooms child live big, dream big, and not in fear. They have been handed a tougher hand of cards than others...but, encourage them to play their hand to their highest potential!
- Information online or that you receive from a doctor may not be the most accurate or up-to-date.
- Read the patient & family handbook.
- Switch doctors if need be to find someone who is supportive and willing to go the extra mile and learn about Bloom syndrome.
- Don't focus only on health issues – enjoy life and try not to be too protective.
- Talk to other families, to get information, and to have a support system.
- Be supportive and proud of your child.
- Enjoy the ride and wear sunscreen!

Session Wrap-Up

Thanks for attending!

- Join us on July 22nd for **Current Research on Bloom Syndrome**, with presentations from Nathan Ellis, Joanna Groden, and Chris Cunniff.
- And lastly, a poll to get your feedback on today's session.
- Feedback or questions? Email us at info@bloomssyndromeassociation.org

