



**2022 Bloom Syndrome  
Patient & Family Conference**

**August 5-7**

**Chicago, Illinois, USA**



# Conference Welcome & Overview

Mary Beth Campbell  
Susan Zaslav

# Agenda

- Welcome!
- Background of BSA
- Preview of Conference Agenda
- Conference Logistics
- Note of Thanks for Sponsors & Donors





**Welcome to Chicago!**

# The Bloom Syndrome Community is made up of many groups



**Bloom Syndrome  
Association**



Volunteers



Doctors



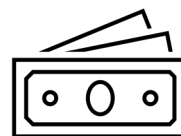
Patients & Families



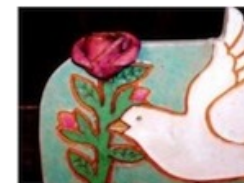
Researchers

**BLOOM'S  
SYNDROME  
FOUNDATION**

**Bloom's Syndrome Registry**



Donors



Bloom's Connect

The BSA was formed in 2012 to help make connections, with patients & families at the center



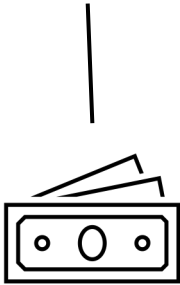
Susan & Paul Zaslav



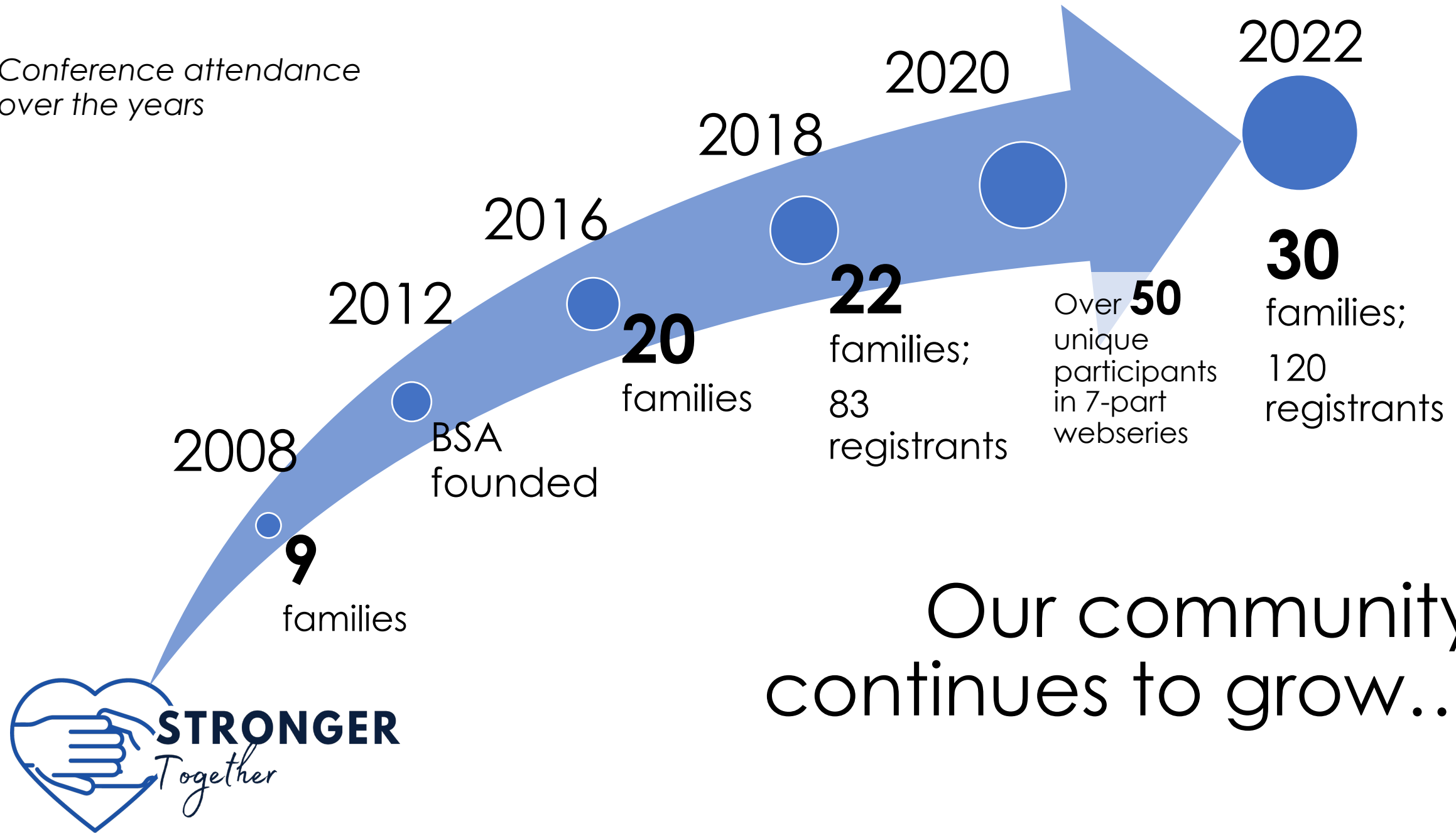
Patients & Families



# We want to continue to build and deepen ties to meet our mission



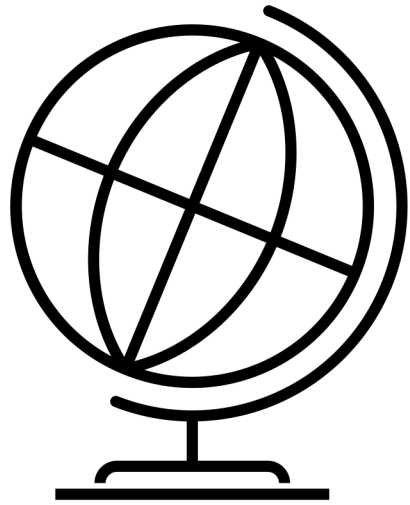
Conference attendance  
over the years



Our community  
continues to grow...







**203**

members of  
the Bloom  
Syndrome  
Community  
Facebook  
page

**274**

individuals on  
the BSA  
mailing list

**411**

constituents  
from over

**15** countries

...in person and virtually,  
around the world!



**Our mission is to connect, educate, and support the international Bloom syndrome community and stimulate research that leads to longer, healthier lives.**



# Saturday Morning

8:30am – 9:00am      Conference Welcome  
*Presenters: Mary Beth Campbell, Susan Zaslav*

9:00am – 10:00am      Getting to Know You! Community Introductions  
*Facilitator: Lorne Yasbin*

10:00am – 10:30am      Networking/Refreshment Break

10:30am – 11:30am      Raising a Child with Bloom Syndrome: Being an Effective Advocate - Panel Discussion  
*Moderator: Jodie Madry*

11:30am – 12:00pm      Group Photo  
Location: To be announced

12:00pm – 1:00pm      Buffet Lunch  
Location: Atrium (Level 2)





# Saturday Afternoon/Evening

1:00pm – 2:00pm Growing Up with Bloom  
Syndrome: When Your Age Doesn't Match Your  
Size – Panel Discussion  
*Moderator: Leslie Ryan*

2:00pm – 3:00pm Stronger Together: Teaming Up  
Against Cancer  
*Presenters: Vivian Chang, MD; Lisa Wang, MD*

3:00pm – 3:30pm Networking/Refreshment Break

3:30pm – 4:15pm Bloom Syndrome Research  
Updates  
*Presenters: Nathan Ellis, PhD; Joanna Groden,  
PhD; Jalees Rehman, MD*

4:15pm – 5:00pm Bloom Syndrome Registry  
Update  
*Presenter: Christopher Cunniff, MD*

5:00pm – 6:00pm Free time

6:00pm – 8:00pm Group Dinner  
Location: Five Roses Pub, 5509 Park Pl, Rosemont  
Within walking distance of the hotel

8:00pm – 10:00pm Young Adult Get-Together (21  
years and older)  
*Organizer: Lexi Ryan*  
Location: Gibsons Bar & Steakhouse, 5464 N River  
Rd, Rosemont

8:00pm – 10:00pm Teen/Pre-Teen Movie Night  
*Chaperones: Talon and Annie Webb, Susan  
Zaslaw*  
Location: Boardroom East (Level 1)



# Sunday

8:00am – 12:00pm Childcare/Kids' Activities  
Location: Salon Rooms A-B (Level 1)

8:30am – 9:15am Managing  
Immunodeficiency in Bloom Syndrome  
*Presenter: Edith Schussler, MD*

9:15am – 10:15am BSA Update: Building for the  
Future  
*Presenters: Mary Beth Campbell, Leslie Ryan,  
Talon Webb,  
Lorne Yasbin, Susan Zaslav*

10:15am – 10:45am Networking/ Refreshment  
Break

10:45am – 11:30am What's On Your Mind? –  
moderated attendee discussion  
*Moderator: Talon Webb*

11:30am – 11:45am Closing Remarks  
*Presenter: Mary Beth Campbell*

11:45am – 12:00pm Conference Survey  
*Facilitator: Susan Zaslav*

12:00pm – 1:00pm Lunch (box lunches)  
Location: Atrium Grove (Level 2)

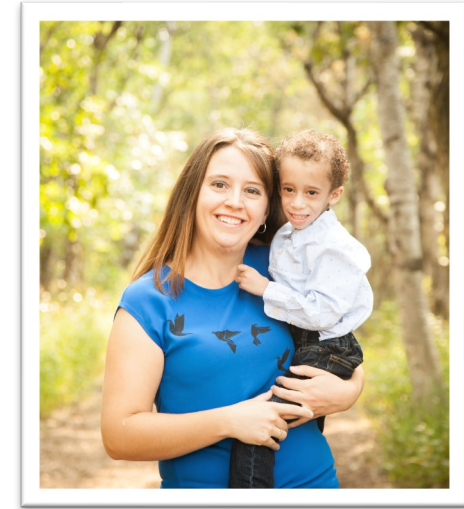
1:00pm – 1:30pm Free time

1:30pm – 5:00pm Family Recreation  
Activity (optional)  
Location: Urban Air Adventure and Trampoline  
Park  
7401 West 25th St, North Riverside  
Bus transportation will be provided to/from  
Urban Air.

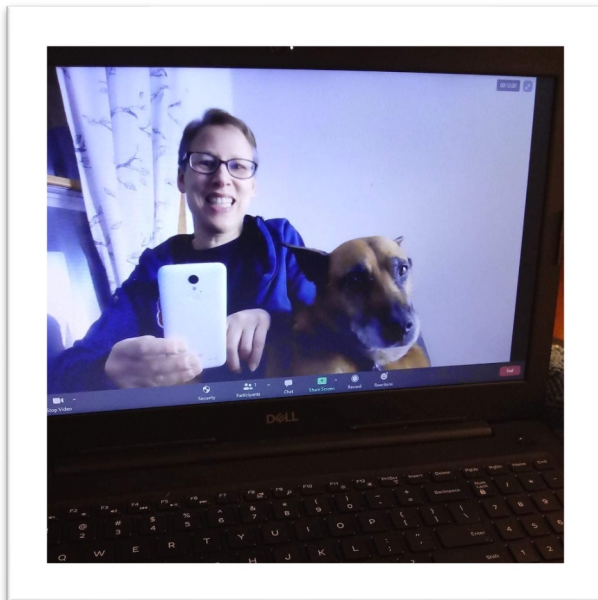
# Logistics

- Photographer
- Videographer
- No private live streaming
- Question board/Post-it notes
- Questions encouraged! We want this to be interactive.
- Use of microphones
- Covid safety & preferences
- Conference contacts





**Thank you to the  
Event Management  
Team and all other  
BSA Volunteers!**



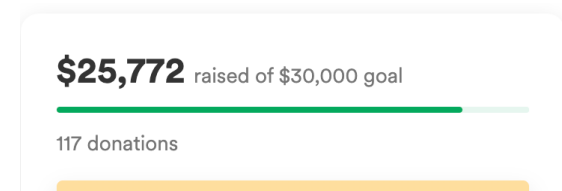


**Thank you to our  
sponsors and  
donors!**

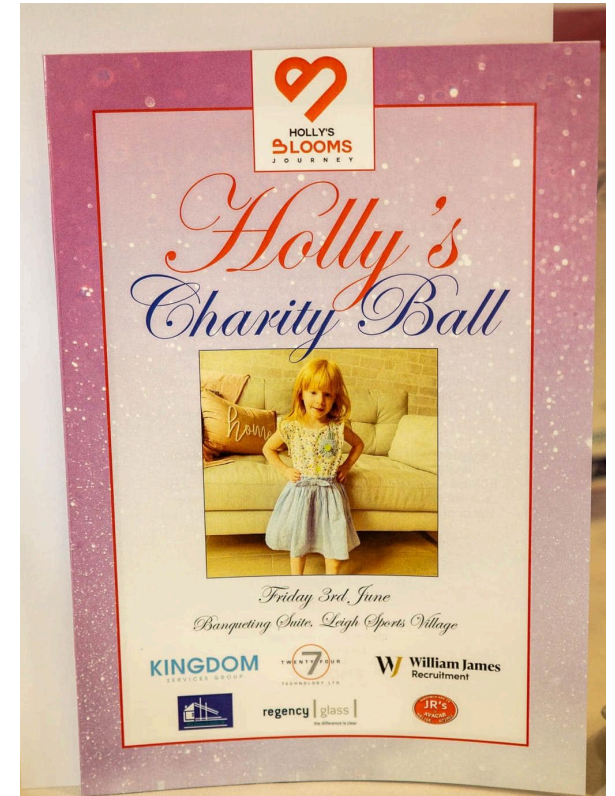


*And many donations made by BSA members, their families and friends!*

**Bloom Syndrome  
Registry**







# Networking/Refreshment Break

- Refreshments are at the back of the room.
- Next session starts promptly at 10:30.





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# **Getting To Know You! Community Introductions**

**Lorne Yasbin (Moderator)**

**Sylvia Campbell**

**Wes Campbell**

**Bob Campbell**

**Annie Webb**

# Questions

1. What is your name and where do you live?
2. What is your relationship to Bloom syndrome?
3. What is something unique about yourself you'd like to share?
4. You are at the airport and can go anywhere. Where are you going and why?
5. What is your favorite food/restaurant/drink?



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## **Raising a Child with Bloom Syndrome: Being an Effective Advocate**

**Jodie Madry (Moderator)**

**Wes Campbell**

**Paula Hesch**

**Eileen Rosenthal**

**Joe Ryan**

**++1 more**



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# **Growing up with Bloom Syndrome: When Your Age Doesn't Match Your Size**

**Leslie Ryan (Moderator)**

**Izzy Madry**

**Rachel Rosenthal**

**Christian Ryan**

**Lexi Ryan**

**Victoria Warren**



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# **Stronger Together: Teaming Up Against Cancer**

**Vivian Chang, MD**

**Lisa Wang, MD**



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# **Bloom Syndrome Research Updates**

**Nathan Ellis, PhD**

**Joanna Groden, PhD**

**Jalees Rehman, MD**



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# **Bloom Syndrome Registry Updates**

**Chris Cunniff, MD**

**Nicole Kucine, MD**