

# Stepping **FORWARD**

2020 Bloom Syndrome Conference



Webinar  
Series

## Session 1: Getting to Know Our Community

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JUNE 10, 2020



# Webinar Logistics

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- The presentation portion of this webinar will be recorded.
- Please mute your microphone unless you are speaking.
- Please save your questions until the Q&A period after the presentation.
- Zoom questions during the session? Use the **Chat** feature in Zoom to request assistance from the person who is labeled as **tech support** in the participant list.
- We will post a recording of this session on the BSA website.



# Session Objectives

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- Become comfortable with the Zoom webinar platform
- Learn about the BSA and what it's been up to
- Learn about the upcoming webinars
- Get acquainted with other members of the Community



# Webinar Agenda



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- Session objectives – Leslie Ryan
- Bloom Syndrome Association update – Susan Zaslav
- Q&A – Leslie Ryan
- Website Demo – Paul Zaslav
- Wrap-up – Leslie Ryan
- Attendee meet & greet – Leslie Ryan



# Zoom 101 – Yes/No Questions

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- The Yes/No feature is an easy way to get quick answers from attendees.
- Let's try it: [Is this your first time using Zoom?](#)
- Click on the **Participants** icon at the bottom of your Zoom window.
- Click on the  or  button at the bottom of the Participants list to indicate your answer.
- Easy, right?



# Zoom 101 – Chat

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- The Chat feature in Zoom allows you to communicate with everyone or a single individual during the webinar.
- Let's try it:
- Click on the **Chat** icon at the bottom of your Zoom window.
- Select **Everyone** from the drop-down list in the Chat window, then **post a message with your name, State/Province and Country.**



# Bloom Syndrome Association Update

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- Presenter: Susan Zaslav



# Bloom Syndrome Association Update

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- BSA today
- Brief history of the BSA
- BSA strategic priorities





# The Bloom Syndrome Community

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Healthcare providers



Patients & Families

BLOOM'S  
SYNDROME  
FOUNDATION

Researchers



Bloom's  
Connect

# Bloom Syndrome Association Today

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- 501(c)(3) nonprofit organization in the U.S. providing international patient & family services and support

	<b>Members</b>	<b>Mailing List Only</b>
<b>BSA Community</b>	105	27
<b># Affected Individuals</b>	30	3
<b># Families</b>	70	6
<b># Others</b>	22	10

Note: Adults only



# Meet the BSA Board of Directors

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- Mary Beth Campbell
- Chris Cunniff, MD
- Stacey Dentz
- Nathan Ellis, PhD (Vice President)
- Richard Gladstein
- Barry Halpern (Treasurer)
- Leslie Ryan (Secretary)
- Paul Zaslav (President)
- Susan Zaslav



# BSA Online Presence

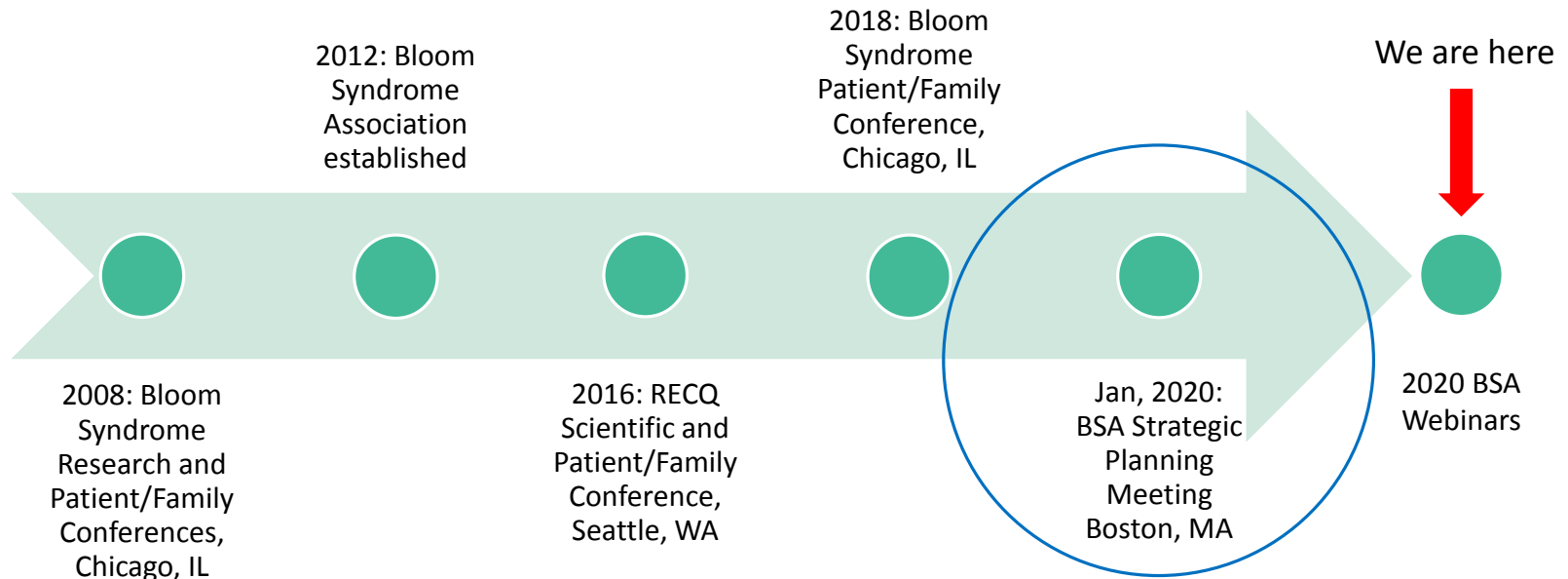
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- Website: [www.bloomssyndromeassociation.org](http://www.bloomssyndromeassociation.org)
- Facebook page: Bloom Syndrome Association
- Facebook group: Bloom Syndrome Community
- Twitter: bloomsynassoc
- Instagram: bloomsyndrome



# The Bloom Syndrome Association Journey

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# Strategic Planning Meeting Objectives

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- Discuss and affirm the mission of the BSA.
- Strengthen the Association's organizational structure, governance and operations.
- Identify short-term and long-term strategic priorities.
- Develop action plan for implementing short-term strategic priorities.



# Updated BSA Mission Statement

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“The mission of the BSA is to connect, educate, and support the international Bloom syndrome community and stimulate research that leads to longer, healthier lives.”



# Identify Short/Long-Term Strategic Priorities

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## Short-Term Priorities

- Host a 2020 patient & family conference
- Formalize organizational governance and operations
- Establish a medical-scientific advisory board (MSAB)
- Form a Bloom Syndrome Registry Task Force
- Create working groups to assist with the operations of the organization, e.g., communications, fundraising

## Long-Term Priorities

- Create a 3-year strategic plan
- Develop programs around:
  - Patient & family engagement
  - Research
  - Patient & family services
  - Advocacy
  - Healthcare provider education
- Support regional patient & family meetings
- Modernize website





# Stepping **FORWARD**

2020 Bloom Syndrome Conference



~~2020 Bloom Syndrome Conference~~  
Webinar  
Series



# 2020 Stepping Forward Webinar Series

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- **June 10:** BSA Update and Community Meet & Greet
- **June 24:** Cancer Surveillance and Treatments in Bloom Syndrome
- **July 8:** Parenting a Child with Bloom Syndrome
- **July 22:** Current Research on Bloom Syndrome
- **August 5:** Living with Bloom Syndrome: Telling Your Story
- **August 19** (tentative): Immunology, Endocrinology, and Bloom Syndrome
- **September 2:** Stepping Forward: The Next Generation of the Bloom Syndrome Association

All webinars will run 60-90 minutes  
and begin at 8:00pm GMT



# Presentation Q&A

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# BSA Website Demo

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[HTTPS://WWW.BLOOMSSYNDROMEASSOCIATION.ORG](https://www.bloomssyndromeassociation.org)

## Key Resources

- Patient & Family Handbook
- Bloom Syndrome Health Supervision Guidelines\*
- Bloom syndrome information
- Research information
- Medical & Scientific Publications
- Ask the Registry feature
- BSA newsletter
- Related resources information
- Member directory\*

\* Requires member login to access

# Presentation Wrap-Up

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- Join us on June 24 for **Cancer Surveillance and Treatments in Bloom Syndrome**, moderated by Chris Cunniff, MD, and featuring Vivian Chang, MD, from UCLA.
- Zoom poll – tell us what you think of today’s session
- Meet & Greet!



# Attendee Meet & Greet

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- Let's start with introductions.
  - What's your name?
  - Where do you live?
  - What's your connection to Bloom syndrome?

