

Stepping **FORWARD**

2020 Bloom Syndrome Conference



Webinar
Series

Session 7: Stepping Forward - The Next Generation BSA

SEPTEMBER 2, 2020



Webinar Agenda

- Objectives – Leslie Ryan
- The Big Picture – Leslie Ryan
- Community Needs Assessment Results – Mary Beth Campbell
- Next Gen BSA: Stepping Forward – Susan Zaslav
 - Next steps
 - Volunteer opportunities
 - Other ways to support the community
- Webinar Reflections – Leslie Ryan



Session Objectives

- Ground all of us on what we've done to date
- Learn about results of community needs assessment
- Learn about changes the BSA is making to respond to community needs
- Learn about opportunities to help the BSA step forward



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Session 1: Getting to Know Our Community

Session 2: Cancer Surveillance and Treatments

Session 3: Parenting a Child with Bloom Syndrome

Session 4: Current Research on Bloom Syndrome

Session 5: Living with Bloom Syndrome – Telling Your Story

Session 6: Immunology, Endocrinology and Bloom Syndrome

Session 7: Stepping Forward – The Next Generation BSA

The Big Picture: Why are We Doing This?



The Impossible is Possible – It's Up to Us!

<https://www.facebook.com/watch/?v=1530650690395570>



The Big Picture: What is Our Goal?

“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.”



The Big Picture: Our Strategic Priorities

Short-Term Priorities

- ✓ Host a 2020 patient & family conference webinars
- 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

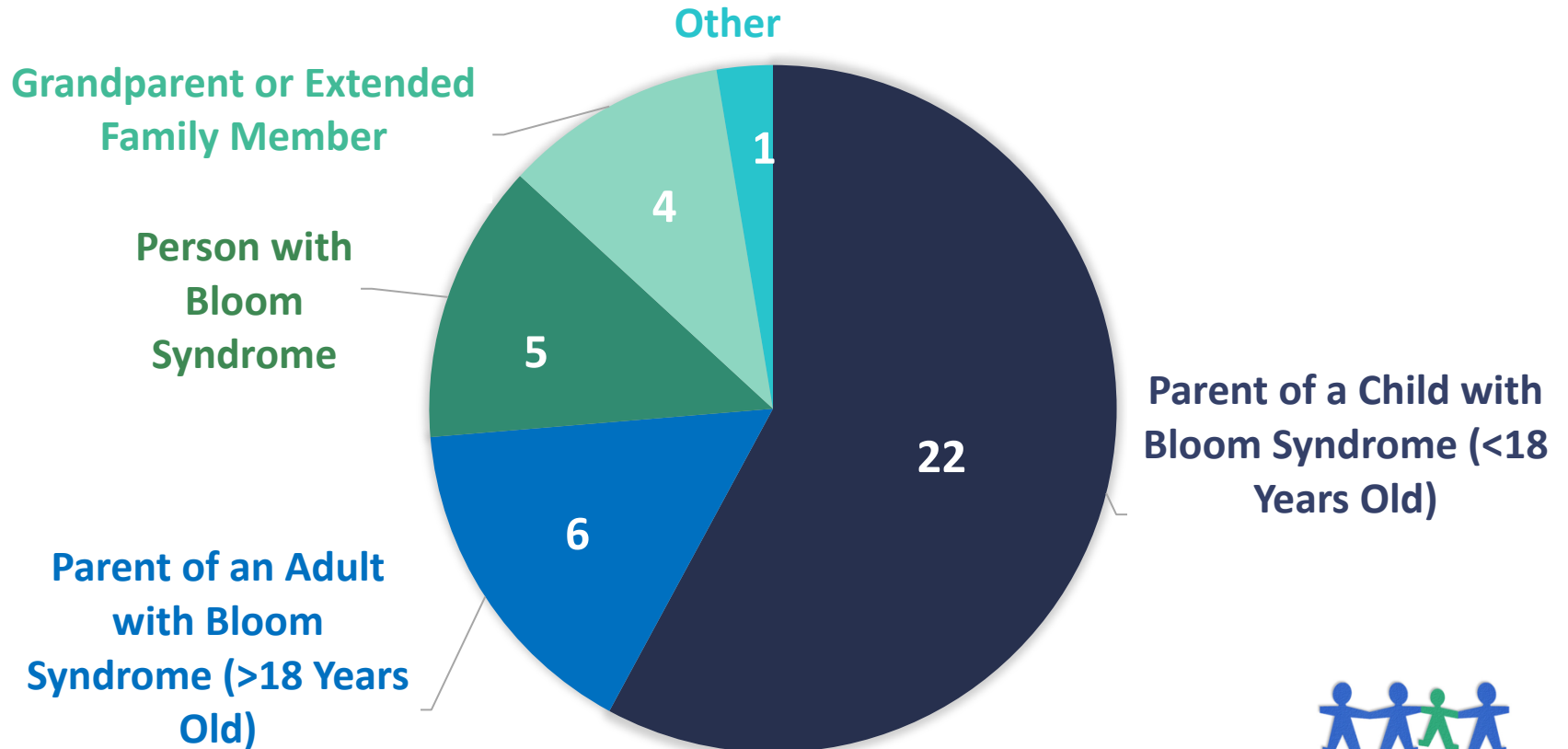
- Create a 3-year strategic plan
- Develop programs around:
 - Patient & family engagement
 - Research
 - Patient & family services
 - Advocacy
 - Healthcare provider education
- Support regional patient & family meetings
- Modernize website



Community Needs Assessment



38 Respondents



Respondents from (at least) 7 countries!



What Does the Community Want?

Highest
Priority

- Patient and Family Handbook (3.78)
- Research Updates from the MSAB (3.61)
- Updates from the Registry (3.45)
- International Family Conferences (3.32)
- Webinars (2.74)
- Social Media Interactivity (2.66)
- Peer Mentoring (2.59)

(Weighted
Average of
Priority)
5 = Highest
4 = Medium-High
3 = Medium
2 = Low
1 = Not a Priority



What Does the Community Want?

Lower
Priority

- Regional Family Conferences (2.51)
- Newsletter (2.32)
- Active Blog (2.24)

We will seek to implement all programs,
but we need your help!



Volunteering

- 30 (~80%!) respondents indicated a willingness to volunteer
 - Some people did not list their contact information!
- Susan will present specific opportunities
- If you don't hear from us or have additional thoughts after today's webinar, email board@bloomssyndromeassociation.org



Other Results

- Some respondents were not sure how to enroll in Bloom Syndrome Registry → Email Dr. Chris Cunniff (cmc9039@med.cornell.edu)
- Interest in connecting with other members by country → the BSA can help!
- Educating healthcare providers on Bloom syndrome → a future priority



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Stepping Forward Objectives

1. Strengthen Governance & Operations (BSA Board)
2. Establish Standing Committees
3. Establish Registry Task Force
4. Establish Technology Needs Task Force



BSA Board of Directors

Planned changes

- 7 voting members, 1 non-voting
 - Chair
 - Vice Chair
 - Secretary
 - Treasurer
 - General Members (3)
 - Executive Director (non-voting)
- Board to include:
 - At least one individual with Bloom syndrome
 - At least one parent of an individual with Bloom syndrome
 - Representatives from at least two countries



BSA Board of Directors

Planned changes (cont'd)

- 3-year terms for all positions
- 2-term (consecutive) limit
- First term begins in January
- Application process
- Formalized responsibilities
 - Fundraising goals: Give or get
 - Committee service
 - Quarterly meetings
 - Officer-specific duties
- Estimated Time Commitment
 - 8-12 hrs/mo



BSA Board of Directors

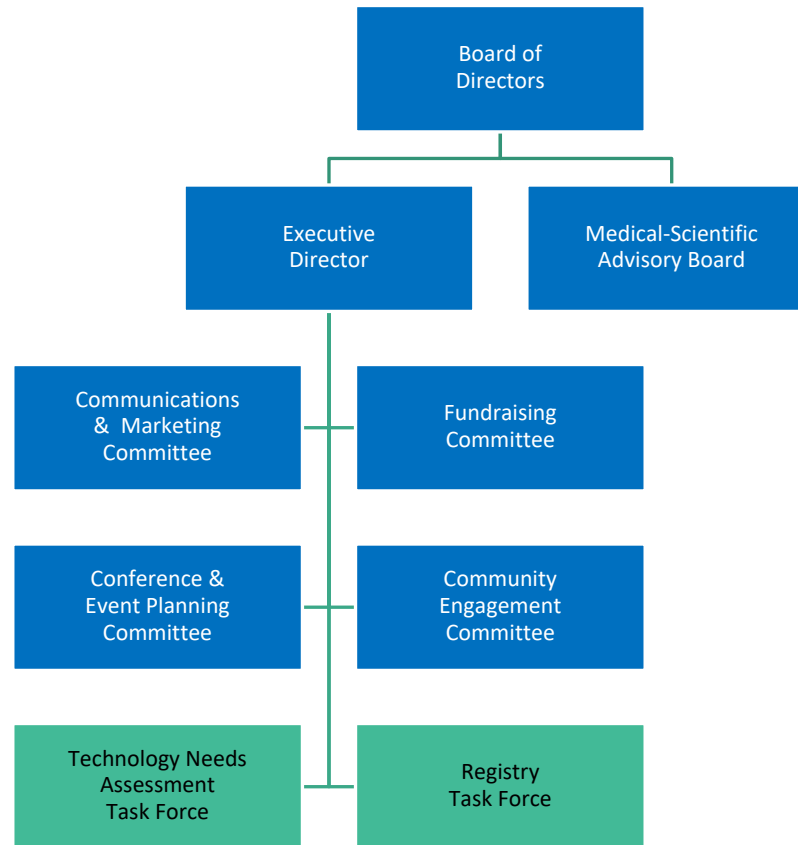
- Timeline for changes
 - October 1: Call for Board applications
 - October 31: Board position applications due
 - November 15: Approve new Board members
 - December 15: Complete new Board member orientation
 - January 1, 2021: New Board members installed
- How to get involved?
 - Look for Board application announcement in early October.
 - If interested, submit application by October 31.

Standing Committees & Task Forces

- What is a Standing Committee vs. a Task Force?
- Committee/Task Force structure
 - Chairperson
 - Members
 - Board member liaison
- Expected time commitment?
 - Will depend on activities, but not meant to be large time commitment: ~4 hrs/mo
 - Do hope for 1-2 year commitment, for continuity's sake



Standing Committees & Task Forces



Communications & Marketing

- Some Responsibilities
 - Developing "brand" of BSA
 - Serving as resource for other committees and community members
 - Developing annual plan
- Potential Outputs
 - Active social media presence
 - Blog (supporting others to contribute content)
 - Newsletter
- Desired skills & background
 - Marketing and graphic design
 - Social media management
 - Writing skills



Fundraising

- Responsibilities
 - Leading fundraising campaigns for specific BSA programs & activities
 - Developing fundraising “toolkit” for community
 - Developing donor strategy and retention guidelines
 - Developing annual plan
- Potential Outputs
 - Dollars raised
 - Fundraising “toolkit”
 - Donor stewardship processes
- Desired skills & background
 - Development
 - Administrative



Conference & Event Planning

- Responsibilities
 - Support all aspects of International Patient & Family Conferences
 - Possibly develop content for ongoing Webinars
 - Support members in hosting Regional Conferences
- Potential Outputs
 - Conference "playbook" for future conferences
 - Events
- Desired skills & background
 - Administrative (project management)
 - Organization & planning skills



Community Engagement

- Responsibilities
 - Programs that encourage patient/family involvement in the BSA
 - Outreach to new and existing members
 - Ongoing assessment of community needs
- Potential Outputs
 - Peer/Family Mentoring Network
 - “Welcome” kit for new members
 - Support in translation to other languages
- Desired skills & background
 - Emotional intelligence
 - Good communication skills



Technology Needs Task Force

- Expected timeline – sooner rather than later
- Responsibilities
 - Evaluate current BSA (including standing committees') technology needs
 - Explore technology solution options
- Potential Outputs
 - Recommendations to the BSA on technology portfolio & ongoing organization for handling technology
- Desired skills & background
 - Comfort with technology



Registry Task Force

- Likely to evolve into standing committee
- Responsibilities
 - Examine current status and future strategy, maintenance, and growth of Registry
 - Including understanding community & research needs for Registry
- Potential Outputs
 - Report to BSA on recommendations
- Desired skills & background
 - Good communication skills



Summary of Volunteer Opportunities

- Board membership: 3 year terms
- Standing committees: 1-2 year commitments
- Shorter-term efforts:
 - Registry Task Force
 - Technology Needs Task Force
- We need your help!
 - If you indicated a willingness to volunteer, look for an email within the next few weeks
 - Email board@bloomssyndromeassociation.org



Other Ways to Support the BSA

- Amazon Smile
- Birthday/special occasion fundraisers
- Post in Bloom Syndrome Community FB group
- Enroll in the Bloom Syndrome Registry
- Sign up for BSA membership (it's free!)
- Share photos on BSA website



Next Steps/Timeline

- Committee/Task Force Establishment: by 12/31/2020
- New Board Members: by 12/31/2020
- Quarterly webinar: Early December



Webinar Reflections

- What was your favorite webinar and why?
- What were your "a-ha" moments?
- What impacted you most significantly?
- What do you need more of (either data-wise or support-wise)?
- What do you want to learn more about?
- What do you wish you had said that you didn't?



Thank you!

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