Visit the BSA Website

The Bloom Syndrome Association has grown significantly over the past two years. As we prepare to gather in Los Angeles for the 2026 Blossoming Hope Conference, we are also taking time to listen, learn, and plan thoughtfully for what comes next.

This quarter's newsletter highlights work underway across the BSA: strategic planning, the upcoming Blossoming Hope Conference, the Bloom-Rx scientific and clinical workshop, the International Bloom Syndrome Registry, research funding, clinical care initiatives, mental health support, and opportunities for every family and supporter to be part of the momentum.

Most importantly, this next chapter will be shaped with the Bloom syndrome community. We hope you will read, share, register, participate, and tell us what matters most to you.

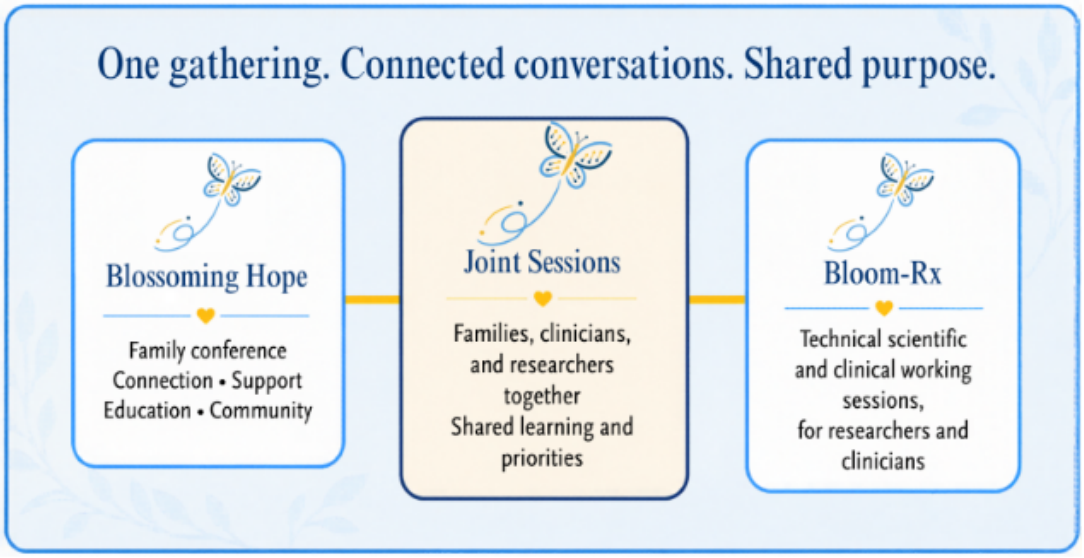
SHAPING THE FUTURE OF THE BSA - TOGETHER

The BSA is currently engaged in a strategic planning process to help guide the organization's next stage of growth. Over the past two years, the BSA has expanded its work in research, clinical engagement, community support, fundraising, and organizational infrastructure.

That growth brings an important responsibility: to pause, listen, and make sure our priorities reflect the needs of the people and families we serve.

This growth has been made possible by families, donors, volunteers, clinicians, and researchers who believe that even a very rare disease deserves organized, ambitious, and sustained action. The BSA is engaged in a strategic planning process to help guide its next stage of growth. This process will include Board and Research Council input, stakeholder conversations, and discussion at the Blossoming Hope Conference. As the BSA grows, we are also investing in planning, financial oversight, and operational systems so that donor support is used responsibly and strategically.

We look forward to sharing more after this process is complete. For now, we are grateful to everyone contributing time, perspective, and hopes for the future of the BSA.



BLOSSOMING HOPE AND BLOOM-RX: BRINGING FAMILIES, CLINICIANS, AND RESEARCHERS TOGETHER

This summer, the BSA will gather in Los Angeles for the 2026 Blossoming Hope Conference, July 31-August 2, 2026. The conference will be an important opportunity for families, individuals living with Bloom syndrome, clinicians, researchers, Board members, Research Council members, and supporters to connect in person.

Alongside the family conference, the BSA will also convene Bloom-Rx, a focused scientific and clinical workshop for researchers and clinicians working on Bloom syndrome. Bloom-Rx includes technical scientific and clinical sessions designed for medical and research exchange. These working sessions will help strengthen collaboration, deepen shared understanding of Bloom syndrome biology and clinical care, and identify opportunities to accelerate research and future treatments.

Families remain central to this work. The insights and relationships developed through Bloom-Rx will help inform shared conversations during the conference, including joint sessions where families, clinicians, and researchers can learn from one another. These shared sessions are intended to ensure that research continues to be shaped by the lived experience, questions, and priorities of the Bloom syndrome community.

REGISTRATION GUIDANCE:

- Families and community members should register for the Blossoming Hope Conference.
- Researchers and clinicians participating in the technical Bloom-Rx sessions will receive separate information about those sessions.
- Everyone is encouraged to participate fully in the shared conference opportunities designed to bring families, clinicians, and researchers together.

bloom syndrome
#blossominghope

YOUR VOICE WILL HELP SHAPE WHAT COMES NEXT

At this summer's Blossoming Hope Conference and via a pre-conference survey, the BSA will invite families, individuals living with Bloom syndrome, caregivers, clinicians, researchers, and supporters to share what they most want to see from the BSA in the years ahead.

We want to hear from you. What kinds of support would be most helpful to families? What questions should Bloom syndrome research prioritize? What would better clinical care look like? What tools, resources, or connections would make the biggest difference? How can the BSA better serve an international community?
These conversations will help inform the BSA's strategic planning, Research Council priorities, future family resources, and long-term research strategy. Whether you are attending the conference in person or following the BSA's work from afar, your perspective matters.

START THINKING NOW:

- What support, education, or connection would help you most in the next year?
- What do you wish every doctor understood about Bloom syndrome?
- What research question feels most urgent to your family?

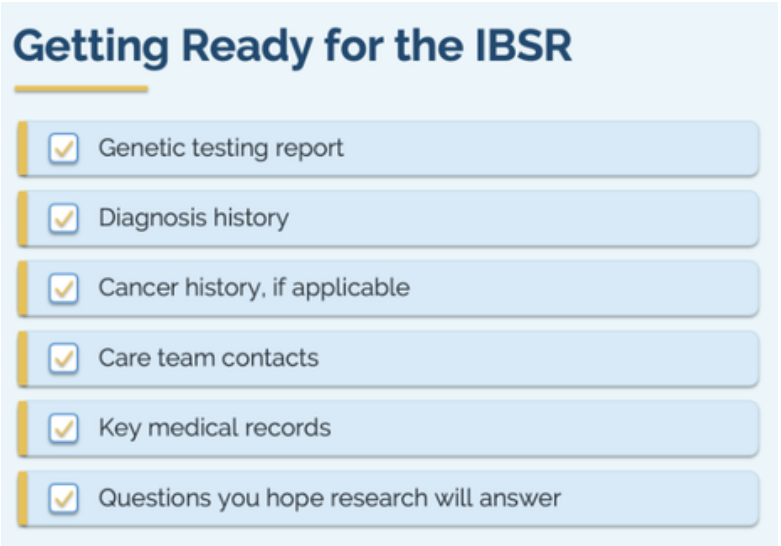
THE INTERNATIONAL BLOOM SYNDROME REGISTRY IS MOVING TOWARD LAUNCH

The BSA continues to prepare for the launch of the International Bloom Syndrome Registry (IBSR), a secure online platform designed to help us learn, together, from every Bloom syndrome story.

The IBSR is intended to support better understanding of how Bloom syndrome affects people over time, how cancers and other health issues are treated, and how care and research can improve. The registry is also an important foundation for future natural history studies, clinical research, and potential trials.

The initial launch will focus on information shared by individuals with Bloom syndrome and caregivers through a protected platform being developed in partnership with the National Organization for Rare Disorders (NORD). Over time, the BSA hopes the IBSR can support additional types of information, including clinician-reported data, automated importation of medical records, genetic information, and other research data where appropriate and with proper consent and oversight.

The IBSR is currently moving through required ethical review and launch preparation, with expected launch in July. Once approvals and setup are complete, the BSA will share details about who can participate, how to enroll, and what families can expect.



2026 SEED GRANT PROGRAM LAUNCHES WITH A TRANSLATIONAL FOCUS

The 2026 Seed Grant Program has launched, continuing the BSA's commitment to supporting research that can improve understanding, care, and future treatment options for individuals living with Bloom syndrome.

In 2024, the BSA awarded three seed grants to support projects focused on cancer surveillance, Bloom-associated tumors, and gene modification strategies. These grants were designed to do what seed funding does best: help researchers generate the early data needed to answer critical questions and position promising projects for larger follow-on funding.

The 2026 Seed Grant Program builds on that same approach, with an even sharper focus on research that can move the field toward therapeutic development. Areas of interest may include therapeutic concepts, model systems, cancer treatment safety, drug repurposing, gene or mutation-targeted approaches, biomarkers, and tools that could help prepare the field for future clinical studies.

In addition to research funding, the BSA aims to serve as a partner in making Bloom syndrome research more connected, collaborative, and patient-centered. That means helping researchers engage with the patient and family community, connect with other investigators and clinicians, and make use of emerging BSA-supported infrastructure, including the International Bloom Syndrome Registry, biospecimen resources, clinical insights and networks, and collaborative research opportunities.

Seed funding is not the end point. It is one way the BSA helps promising Bloom syndrome research become competitive for larger grants, partnerships, and therapeutic development.

BUILDING TOWARD BETTER BLOOM SYNDROME CARE

Research is essential, but families also need better care now. The BSA is working to better understand what coordinated, knowledgeable Bloom syndrome care can look like and how families can be connected to clinicians who understand the condition.
One important area of learning is multidisciplinary clinical care. Early clinic-based efforts, including work at UCLA and in the UK (in London and Manchester), are helping the BSA and its clinical partners understand what families need most when multiple specialists are involved in care. Coordinated care can help reduce fragmentation, support more informed clinical decision-making, and identify common questions that may benefit from shared resources or future guidance.

The BSA is also exploring what Centers of Excellence or designated clinical partner models could look like for Bloom syndrome. These models could help connect families with knowledgeable care teams, support education for local clinicians, contribute clinical insights to research, and strengthen collaboration across institutions and countries.
This work is still developing, and the BSA has started by listing clinics on its website as a first step. But the goal is clear: to move toward a future in which families are not left to navigate Bloom syndrome care alone.

CONNECTING CLINICIANS AROUND BLOOM SYNDROME CANCERS

Cancer care is one of the most urgent and complex areas of Bloom syndrome. Through the Hesch Hope Project and related Virtual Tumor Board efforts, the BSA is working to connect clinicians with experience in Bloom syndrome, cancer biology, genetics, and treatment decision-making.

The goal is to support expert discussion of challenging Bloom syndrome cancer cases, help treating physicians think through complex care questions, and learn from cases over time. This work also connects to broader BSA priorities, including the International Bloom Syndrome Registry, cancer-focused research, and efforts to improve treatment strategies for individuals with Bloom syndrome.

The Virtual Tumor Board is not a replacement for a treating physician's medical judgment, and it does not provide direct medical advice. Rather, it is part of the BSA's broader effort to build a more connected clinical and research community around Bloom syndrome cancers. Clinicians caring for a person with Bloom syndrome and cancer may contact the BSA to learn more about available pathways for connection and discussion.

MENTAL HEALTH MATTERS IN RARE DISEASE

Rare disease advocacy has traditionally focused on diagnosis, treatment, and research. And for good reason; those needs are urgent and ongoing.
But there is another layer to this work. One that is quieter, less visible, and often harder to name. It is the emotional residue of navigating a system that does not yet have clear answers. It is the stress that builds over time. It is the experience of not being fully understood, medically or otherwise. Today that part of the journey is being acknowledged: mental health in Bloom syndrome matters.

The BSA is excited to collaborate with Give an Hour, a national organization dedicated to transforming mental health by building strong and healthy individuals and communities. Through this collaboration, the BSA hopes to support online peer support groups with access to a licensed mental health professional.

More information will be shared as this work develops, and Give an Hour partners will be an integral part of the Blossoming Hope conference this summer.

Give an Hour™
Give help | Give hope

COMMUNITY INFRASTRUCTURE: GLOBAL AMBASSADORS, HANDBOOK, AND HEALTH STRATEGIES

The BSA's community engagement work is also moving forward. The Community Engagement Committee is supporting efforts to improve communication with families, patients, and strategic partners across the international Bloom syndrome community.

One developing effort is the Global Ambassador program, which is intended to create a network of community members who can serve as points of connection for new and existing families in their own countries or regions. Ambassadors may help families connect in a familiar language, understand available BSA resources, and feel less alone after diagnosis.

The BSA is also working on updates to the Patient and Family Handbook and the sharing of a new health strategies document developed by Todd Prince. These resources are intended to help families understand Bloom syndrome, prepare for clinical conversations, and navigate care. They are not a substitute for individualized medical advice, but they can help families and clinicians start from a stronger shared foundation.

Community members interested in volunteering, reviewing materials, helping with translations, or learning more about the Global Ambassador program are encouraged to contact the BSA.

GROWING RESPONSIBLY BEHIND THE SCENES

As the BSA's programs grow, so does the need for strong organizational systems. A tremendous amount of work is happening behind the scenes to ensure that the BSA has the operational capacity and framework necessary to support its mission now and into the future.

As one example, the BSA is undergoing an internal financial review conducted by Forge Financial & Management Consulting to help ensure that the organization's financial practices, processes, and controls are aligned with its growing responsibilities.
This work may be less visible than conferences, research grants, or family programs, but it matters. Strong operations help the BSA steward donor funds responsibly, support complex research and clinical initiatives, and sustain growth over time.

The BSA values the trust that our worldwide community and donors place in us as we continue our mission to connect, educate, and support the international Bloom syndrome community and stimulate research that leads to longer, healthier lives.

LET'S BLOOM TOGETHER

On May 1st we kicked off the Bloom Together campaign, where your monthly recurring gift - as little or as much as you are comfortable with - helps provide support, connection, education, and hope to families affected by Bloom syndrome.

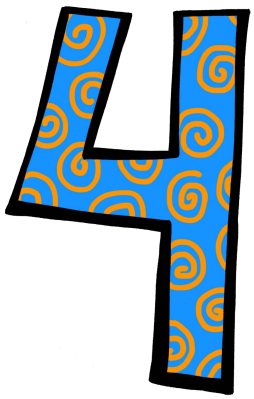
Now here's another way you can help: Friendraise! Many of us are nervous about fundraising but we all have friends, and most of them are likely to be aware of your connection with Bloom syndrome. So, the next time you're taking a walk or having coffee together, share with them how excited you are to have found an easy and affordable way to support the work of the BSA, and invite them to join our community of supporters.

Small gifts add up to big impact. Become a monthly donor today and invite your friends as well! To become a monthly donor, visit the BSA donation page and select the option to make your gift recurring. Helping is empowering. Together, we can help hope bloom.

YOUR SUPPORT IS BUILDING THE FOUNDATION

The BSA's recent growth is not only about doing more. It is about building the foundation to help individuals with Bloom syndrome live longer, healthier lives.

Every gift, volunteer hour, shared connection, and act of advocacy helps move this work forward. This kind of sustained work is only possible because of sustained support. Through Bloom Together, monthly donors help provide the reliable foundation the BSA needs to support families, advance research, and build momentum throughout the year.



WAYS TO BE PART OF THE MOMENTUM THIS QUARTER

- Register for the Blossoming Hope Conference and make plans to join the BSA in Los Angeles.
- Invite a clinician, researcher, or care team member to learn more about the BSA's work.
- Start gathering medical and genetic records that may be useful when the IBSR launches.
- Become a monthly donor, invite a friend to support the BSA, or share the Bloom Together campaign.

2026 BLOOM SYNDROME ASSOCIATION CONFERENCE

Registration is open for the BSA Conference at the Marina del Rey Hotel in Los Angeles, California.
For more information visit our website.

BLOOM TOGETHER: MONTHLY GIVING CAN MAKE A DIFFERENCE!

At the BSA, we know the strength of our community is found in the small acts of love, support, and generosity – all of which add up.

We understand that not everyone can make a large one-time donation—and that's okay. What matters most is showing up in whatever way you can.

Introducing Bloom Together, a monthly giving program designed for families, friends, and supporters who want to make a lasting impact through recurring monthly gifts For $5, $10, or $20 a month, you can help provide:

- Connection and support for families navigating a Bloom syndrome diagnosis
- Educational resources and trusted information
- Research and advocacy efforts that move us closer to better treatments and understanding
- Community programs like Bloom Zooms and our Family Conference

It means we can plan ahead, respond quickly to community needs, and continue building a future filled with hope.

Every gift—no matter the size—helps hope blossom.

Join Bloom Together today and become part of a group making a steady, meaningful difference every month.

Because when we bloom together, we grow stronger.

bloom syndrome
#blossominghope