bloom syndrome association

FROM SEED TO BLOSSOM

In 2008, Paul and Susan Zaslaw, whose daughter had been diagnosed with Bloom syndrome, attended the first ever Bloom syndrome patient, family, and research conference in Chicago, which inspired them to found the Bloom Syndrome Association in 2012.

The seeds were planted. In 2016 members of the Bloom syndrome community participated in the 3rd International Meeting on RECQ Helicases in Biology and Medicine held in Seattle, Washington. That was followed in 2017 when the Children's Cancer Therapy Development Institute sponsored a Bloom Syndrome Nanocourse in Beaverton, Oregon.

Then in 2018, a small but mighty community under the leadership of a dedicated handful of parents and people with Bloom syndrome coalesced into a more structured organization with a professional website, social media presence, formalized relationships with medical professionals and researchers, and a basic virtual infrastructure, and the first bi-annual Bloom Syndrome Conference was held in Chicago.

The BSA continued to grow, sprouting leaves and branching out. When the pandemic made it necessary to cancel the 2020 conference, it was replaced by a seven-session Webinar Series that drew participants from around the world. In 2022 we came back, Stronger Together, once again gathering in person in Chicago.

Two years later, in 2024, we went Beyond Borders for a conference in Frankfurt, Germany, where the BSA announced the budding of a new initiative for patient-centered research steered by a Research Council composed of association members and the research community.

Now we're preparing for the upcoming 2026 conference, where we celebrate Blossoming Hope. From seeds to blossom, we've never been more dedicated to our mission to connect, educate, and support the international Bloom syndrome community and stimulate research that leads to longer, healthier lives.

bloom syndrome #blossominghope

CONNECTING THROUGH FAITH

A few of our community members have been connecting with each other on WhatsApp to encourage each other and pray together in a non-denominational faith-based space, and they welcome others to join them. If this is something you're interested in, contact Victoria Warren on WhatsApp at 1-815-978-1886.

FUNDRAISING IS FRIENDRAISING

On Giving Tuesday, December 2nd, 2025, the BSA in partnership with the Stitching Bloom Syndrome Foundation in the Netherlands kicked off a fundraising campaign. Our first goal post will be February 28th, Rare Disease Day, and so far with YOUR support and matched by generous supporters we have raised over $500,000!

RESEARCH MOMENTUM: YOUR SUPPORT AT WORK

Because of you, Bloom syndrome research is accelerating. We recently announced our first batch of Seed Grant awardees, funded projects that deepen our understanding of Bloom syndrome biology and potential treatments - and generate the data needed to unlock larger grants and partnerships.

At the same time, we are building the critical tools our field has long needed:

- Patient-derived cell lines and iPSCs for therapy testing
- Improved mouse models to study cancer development and evaluate treatments
- Growth of the International Bloom Syndrome Registry (IBSR) to prepare for natural history studies and future clinical trials

Going forward, we will also be funding translational efforts, including:

- Screening FDA-approved drugs for potential benefit in Bloom syndrome
- Exploring mutation-targeted therapies such as ASOs and gene editing
- Studying safer cancer treatment strategies for people with Bloom syndrome

Biomedical research is expensive - but it is how change happens. The funds you donate are being strategically directed toward building infrastructure, launching studies, and accelerating therapies, not sitting idle.

Every dollar is working to move us closer to safer treatments and, ultimately, a cure.

Thank you for making this progress possible.

BSA BOARD NEWS IN BRIEF

The BSA Board of Directors is pleased to announce its 2026 slate and welcome two new members, Eugen Sarbu and Jim Rogers.

Chair - Mary Treder
Vice Chair - Tonja Obermeier
Secretary - Ben Wilson
Treasurer - Jim Rogers

General Member - Victoria Warren
General Member - Candice Bourke
General Member - Eugen Sarbu

Annual budget preparation is underway and we're gearing up for organization-wide facilitated strategic planning among many other things. We're looking forward to an exciting year!

RESEARCH COUNCIL DELIVERABLES PASS THE SIX-MONTH MARK

We have six months to go in our initial term of the Research Council deliverable work! The Deliverables Teams have been asked to assess their progress, what they can reasonably expect to accomplish before the BSA conference in July/August, and propose adjusted action plans at the next Research Council meeting in April. Currently of the nineteen deliverables, fifteen are complete, on hold, or on track. Great work everyone!

GIVE AN HOUR:

The BSA is currently working on developing a partnership with a support organization to help develop peer support groups and provide overall mental health support to our community.

More to come on this as we get established and we are hoping to have them help with the conference this summer as well.

COMING SOON: THE INTERNATIONAL BLOOM SYNDROME REGISTRY (IBSR)

Big news is on the horizon.
This year, the Bloom Syndrome Association will launch the International Bloom Syndrome Registry (IBSR) - a secure online platform designed to help us learn, together, from every Bloom syndrome story.
The goal is simple: To better understand how Bloom syndrome affects people over time, how cancers are treated, and how we can improve care and speed up research.
Individuals with Bloom syndrome (or their caregivers) will be able to securely share medical history, genetic results, and lived experiences through a protected platform built in partnership with the National Organization for Rare Disorders (NORD®).
The IBSR is currently undergoing required ethical review. Once approvals are complete, we'll share details about how to participate.
This effort has been shaped by families, clinicians, and researchers across our community — and we're excited for what it can make possible. Stay tuned!

COMMUNITY ENGAGEMENT

The community engagement committee held their first meeting in February since the relaunch of the group at the beginning of 2026. Some of the highlights from the first meeting:

- Establishing a structure of how the committee will operate and setting core values
- A focus on communication with the community including families, patients, and strategic partners within our network
- Committee is working on an update to the Patient and Family Handbook as well as the launch of a new health strategies guide.

We are also working on developing a Global Ambassador program which will provide a strategic network of community members who will serve as a point of contact for new families and current families within their own country. This will help with communication in a native language as well as halving someone to contact when questions arise.
The community engagement committee is also looking for new members If you are interested in joining please send an email to benwilson@bloomsyndromeassociation.org.

2026 BLOOM SYNDROME ASSOCIATION CONFERENCE:

This years conference will be at the Marina Del Ray Hotel, July 31- August 2, 2026.
We will have registration information available in the next few weeks. We are looking forward to a great conference in July and to seeing everybody there. Stay tuned for more information.

GENETIC COUNSELING STUDENT EXCHANGE (GCSX) PROGRAM.

The Bloom Syndrome Association (BSA) is excited to partner with the UPenn Orphan Disease Center's Genetic Counseling Student Exchange (GCSX) Program.

The GCSX's main object is to engage future genetic counselors in rare disease advocacy and raise awareness about the need to support rare disease foundations and organizations and affected families.

We are proud to introduce Rency Dhaduk as our Genetic Counseling Assistant (GCA) for this year. Rency holds a BS in Genetics and Genomics from UC Davis and is a GCA at Children's Hospital of Philadelphia's Center for Epilepsy and Neurodevelopmental Disorders. During her 10-week tenure as a GCSX intern with the BSA, she will support the development of a comprehensive recruitment guide for individuals with Bloom syndrome by assisting with data collection, analysis, and outreach to key medical and genetic partners, with the goal of expanding participation in the International Bloom Syndrome Registry (IBSR).