Attendees Enjoy Blossoming Hope and Bloom-RX

The 2026 Bloom Syndrome Association Conference: Blossoming Hope, along with Bloom Research Exchange: Bloom-Rx took place from July 31st through August 2nd at the Marina del Rey Hotel in Los Angeles, California. Altogether nearly 150 attendees enjoyed the opportunity to learn, ask questions, share stories, and build connections.

The program covered a broad range of topics including:

- Bloom Syndrome Today – What families should know
- Mental Health and Rare Disease
- The Emotional Impacts of the Diagnostic Journey
- Research Strategy Update
- Emerging Therapies
- And more!

The July 31st conference kickoff marked the first annual Bloom Syndrome Awareness Day, and as the sun set people participated in Light Up for Bloom Syndrome Awareness #Lightup4bsa. Blue lights shone across America, including a bridge in Minneapolis, and around the world in Australia, England, and Mexico.

INTERNATIONAL BLOOM SYNDROME REGISTRY (IBSR)

Since the International Bloom Syndrome Registry opened on July 31, participation has grown rapidly. Today we have participants from 11 countries; 15 are from the US and 20 are from outside the US, including 7 from Poland, with representation from age groups ranging from 0–2 through 55–64 years, and the male/female split is nearly even.

The IBSR is open to people of all ages worldwide who have Bloom syndrome or a Bloom-like syndrome. Parents, caregivers, and other authorized representatives may participate on someone's behalf. As more people join and participants update their information there will be more to share. All public updates use aggregate information and will never identify individual participants or families.

Participation is free, voluntary, and confidential, and surveys can be completed at your own pace. To join or learn more go to https://bloomsyndromeregistry.org .

Ready, Set, Go! Welcome to BLOOMATHON 2026!

Bloomathon is underway, and in the first few days we've raised almost $2,000 dollars! Register at https://secure.qgiv.com/event/bloomathon/ to learn how to fundraise in the way that works best for you.

That's right, raise funds YOUR way. Get super creative and think outside the box…what would get you and your family to participate? A movie night? Car wash? A neighborhood talent show?

Bloomathon runs through the end of the year, so maybe you want to incorporate the holidays in your fundraising efforts! How about a Thanksgiving pie sale? A present wrapping service to your friends and family? A latke cooking contest or a dreidel tournament? Maybe shovel driveways for the cause!

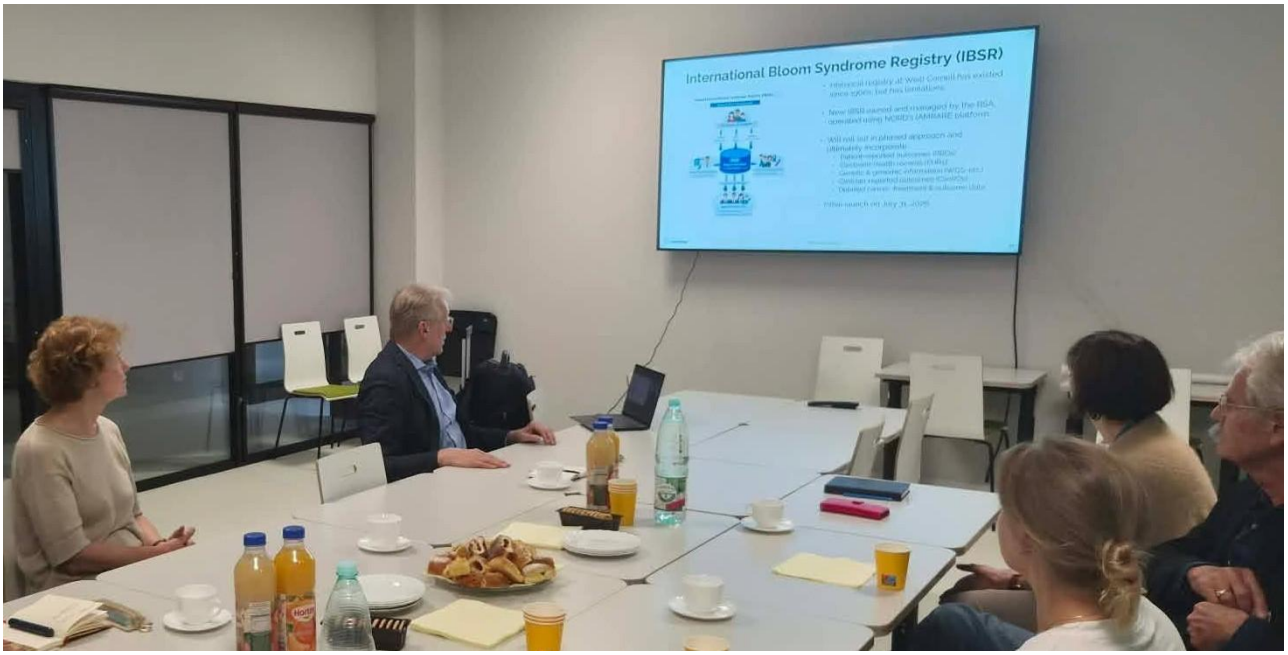
Plus, by choosing Monthly Giving on the Donate page, you and your friends have the opportunity to give a manageable amount every month that will add up to a big gift over time, and as recurring givers you automatically become part of our Bloom Together community!

Joining Forces in Poland to Explore the World of Bloom Syndrome

An inspiring meeting on September 17th in Lodz, Poland attended by Drs. Yves Pommier and Chris Brüengner on behalf of the Bloom Syndrome Association marked an important step toward better understanding and treating Bloom Syndrome. By bringing together experts and families, new opportunities are created for research, support, and international collaboration. It also marked an important step toward the upcoming Euro-Bloom conference in Poland next year.

A particularly important part of the meeting was the sharing of experiences and insights from people with Bloom syndrome. Dorota Pietrzak, Małgorzata Szpot, and Agnieszka Piętera - vice-presidents of the Polish Foundation for Children with Cancer (Fundacja Krwinka) - discussed their experiences and daily life perspectives.

The discussions focused on establishing the framework for further scientific collaboration within the European Rare Disease Research Alliance and creating a space for joint projects. Also discussed was the planned conference in Poland next year, Euro-Bloom. This event will bring together scientists, clinicians, and organizations from around the world and will be an excellent platform for knowledge exchange, experience sharing, and building innovative initiatives.



And in France...

Informer, soutenir, rassembler et créer du lien entre les familles concernées par le Syndrome de Bloom. *Ensemble, pour ne plus être seuls*.

To inform, offer support, bring people together, and foster connections among families affected by Bloom syndrome. *Together, so that no one has to be alone anymore*.

Advocating for Bloom Syndrome

In honor of Rare Cancer Day on September 23rd this year, the Rare Cancer Coalition (RCC) of the National Organization for Rare Disorders (NORD) brought the voices and needs of the rare cancer community to policymakers at both the federal and state levels.

From meeting with congressional offices on Capitol Hill to engaging with state Rare Disease Advisory Councils, RCC members including Ben Wilson of the BSA advocated for policies that can advance rare cancer research, strengthen access to treatments and care, and improve outcomes for people living with rare cancers.

This nationwide advocacy reflects the importance of action at every level of government. The BSA in partnership with NORD is working to ensure the rare cancer community is heard and that continued investment in research and innovation brings hope for better treatments and outcomes.

Following the trip, Ben Wilson was appointed by the State of Colorado to serve a term on the Colorado Rare Disease Advisory Council as a representative of a rare disease patient organization operating in Colorado.

COLORADO
RARE DISEASE ADVISORY COUNCIL

In Loving Memory...

Kerstin Hofstetter passed away on September 5th. She was a gentle person but determined to deal with Bloom syndrome, not only physically and emotionally but also intellectually – as a doctor and as a patient – connecting the Bloom community and her doctors to understand what's going on in Bloom and how to improve care and outcomes.

An award inspired by Kerstin's legacy will be established by the Bloom Syndrome Association to support young researchers doing Bloom syndrome related work.