



2024 Bloom Syndrome Patient & Family Conference

August 2-4
Frankfurt, Germany

Conference Program

2024 Bloom Syndrome Patient & Family Conference

We would like to thank our sponsors for their generous contributions that made this meeting possible.



Bloom Syndrome Registry



The Bloom Syndrome Association also extends our heartfelt gratitude to all the donors whose generous contributions have made the Beyond Borders conference possible. Your support is instrumental in fostering collaboration, innovation, and progress within the Bloom syndrome community. Thank you for your unwavering commitment and dedication.

2024 Bloom Syndrome Patient & Family Conference



Welcome to the 2024 Bloom Syndrome Patient & Family Conference. This is our first conference in Europe and we look forward to making new friends at this year's meeting! Whether you're joining us in Frankfurt or participating online, we are excited to have you attend, and hope that you will be informed and energized by the program we have put together. The Bloom syndrome community is relatively small, but thanks to each of you, we are a cohesive and active support community focused on our members' health and well-being. We look forward to seeing you in August!

Event Management Team

Mary Beth Campbell

Sylvia Campbell

Anne Marie van den Hurk

Jochen Obermeier

Tanja Obermeier

Eileen Rosenthal

Anne Webb

Susan Zaslav (Chair)

Special thanks to Jackie LaHaye for creating the Beyond Borders conference graphic.




2024 Bloom Syndrome Patient & Family Conference

Schedule & Agenda












Unless otherwise noted, all in-person sessions will held be in Salon Rooms 5 & 6.
Virtual attendees who have registered will receive a Zoom link via email by July 26.

Legend: In-person  Virtual  Recorded 

Friday, 8/2/22

5:30pm – 7:30pm	Conference Check-In Restaurant Unterschweinstiege (at conference hotel)	
5:30pm – 7:30pm	Welcome Reception Restaurant Unterschweinstiege (at conference hotel)	
5:30pm – 7:30pm	Childcare/Kids' Activities Providers Meet & Greet Restaurant Unterschweinstiege (at conference hotel)	

Saturday, 8/3/22

7:30am – 8:30am	Conference Check-In (for those who weren't able to Friday evening) Location: Salon Rooms 5 & 6 (ground level)	
8:00am – 11:30am	Childcare/Kids' Activities Location: Salon Rooms 2-4 (ground level)	
8:30am – 8:45am	Conference Welcome <i>Presenter: Christopher Cunniff MD</i>	 
8:45am – 9:30am	Getting to Know You! Group Activity <i>Facilitator: Wes Campbell</i>	 
9:30am – 10:15am	BSA and Registry Updates <i>Presenters: Mary Beth Campbell PhD, Nicole Kucine MD</i>	  
10:15am – 10:30am	Networking/Refreshment Break Location: Meeting room foyer and on Zoom	 


2024 Bloom Syndrome Patient & Family Conference

Legend: In-person  Virtual  Recorded 




Saturday, 8/3/22 (cont'd)

10:30am – 11:30am	The Power of Choice: Thriving with Bloom Syndrome <i>Presenter: Ron Squire LCSW</i>	  
11:30am – 12:00pm	Group Photo Location: In-person photo, to be announced; virtual photo, on Zoom	 
12:00pm – 1:00pm	Buffet Lunch Location: Five Continents Restaurant (ground level)	
1:00pm – 4:00pm	Childcare/Kids' Activities Location: Salon Rooms 2-4 (ground level)	
1:00pm – 2:15pm	Bloom Syndrome and Cancer: Knowledge is Power! <i>Presenter: Vivian Chang MD, MS</i> <i>Special Video Appearances by Lorne Yasbin, Todd Prince, Zak Rogers</i>	  
2:15pm – 3:15pm	The UK Bloom Syndrome National Service: A Model of Specialist Care <i>Presenters: Shehla Mohammed MD, Stefan Meyer MD, Rui Santos MD, Leza Wightman</i>	  
3:15pm – 3:30pm	Networking/Refreshment Break Location: Meeting room foyer and on Zoom	 
3:30pm – 3:45pm	A Roadmap for Living with Bloom Syndrome <i>Presenters: Paula Hesch, Mary Beth Campbell</i>	  
3:45pm – 5:00pm	BSA Olympics! <i>Facilitator: Talon Webb</i> Location: Lawn area outside the hotel	
5:00pm – 6:00pm	Free time	
5:40pm	Optional: Meet in hotel lobby to walk as a group to offsite dinner location	



2024 Bloom Syndrome Patient & Family Conference

Legend: In-person  Virtual  Recorded 

Saturday, 8/3/22 (cont'd)

6:00pm – 8:00pm	Group Dinner Location: Lindbergh's Café (10-15 minute walk from the hotel)	
8:00pm – 10:00pm	Young Adult Get-Together (18-30 years old) <i>Facilitator: Rachel Rosenthal</i> Location: Moxy Bar, Moxy Frankfurt Airport Hotel (Marriott)	
8:00pm – 10:00pm	Teen/Pre-Teen Movie Night (8-17 years old) <i>Chaperones: Talon and Anne Webb</i> Location: Salon Rooms 3 & 4 (ground level)	










Sunday, 8/4/22

8:00am – 12:00pm	Childcare/Kids' Activities Location: Salon Rooms 2-4 (ground level)	
8:30am – 9:25am	Small Group Topical Discussions Location: Salon 5 1. Parenting Young Children with Bloom Syndrome <i>Facilitator: Wes Campbell</i> 2. Growth and Fertility Concerns in Bloom Syndrome <i>Facilitator: Chris Cunniff MD</i> Location: Salon 6 3. Infection and Immunity Concerns in Bloom Syndrome <i>Facilitator: Nicole Kucine MD</i> 4. Other Health Concerns in Bloom Syndrome <i>Facilitator: Shehla Mohammed MD</i> Location: Salon 1 5. Living as an Adult with Bloom Syndrome <i>Facilitator: Victoria Warren</i>	

2024 Bloom Syndrome Patient & Family Conference

Legend: In-person  Virtual  Recorded 

Sunday, 8/4/22 (cont'd)

9:35am – 10:30am	<p>Small Group Topical Discussions </p> <p>Location: Salon 5</p> <p>6. Parenting Teens and Tweens with Bloom Syndrome <i>Facilitator: Anne Marie and Henri van den Hurk</i></p> <p>7. Growth and Fertility Concerns in Bloom Syndrome <i>Facilitator: Chris Cunniff MD</i></p> <p>Location: Salon 6</p> <p>8. Infection and Immunity Concerns in Bloom Syndrome <i>Facilitator: Nicole Kucine MD</i></p> <p>9. Other Health Concerns in Bloom Syndrome <i>Facilitator: Stefan Meyer MD</i></p> <p>Location: Salon 1</p> <p>10. Grieving the Loss of a Loved One <i>Facilitator: Paula Hesch</i></p>
10:30am – 10:45am	<p>Networking/Refreshment Break  </p> <p>Location: Meeting room foyer and on Zoom</p>
10:45am – 11:45am	<p>Advancements in Research: Towards a Patient-Focused Agenda   </p> <p><i>Presenters: Chris Brünger MD, Nathan Ellis PhD, Mary Beth Campbell PhD, Research Roundtable Representatives</i></p>
11:45am – 12:00am	<p>Closing Remarks  </p> <p><i>Presenter: Christopher Cunniff MD</i></p>
12:00pm – 1:00pm	<p>Buffet Lunch </p> <p>Location: Five Continents Restaurant (Ground Level)</p>
1:00pm – 5:00pm	<p>Afternoon Activities (optional) </p> <p>Make a plan to do something fun with other families!</p>

2024 Bloom Syndrome Patient & Family Conference

Session Descriptions

Note: Copies of the speakers' presentations and recorded sessions will be made available on the BSA website after the conference.

Conference Welcome

Presented by Chris Cunniff MD, Chair of BSA Medical-Scientific Advisory Board

Dr. Cunniff will kick off the conference with an overview of the conference agenda and things to know for the next couple of days.

Getting to Know You! Group Activity

Facilitated by Wes Campbell, Bloom syndrome parent

Wes will lead attendees in a fun group activity designed for you to get to know each other.

Updates from the Bloom Syndrome Association & Registry

Presented by:

Nicole Kucine MD, Bloom Syndrome Registry Director

Mary Beth Campbell PhD, Chair of BSA Board of Directors

Join us for an insightful update on the latest Bloom Syndrome Association and Registry activities, highlighting advancements in research, patient support, and community engagement over the past two years. Discover how these initiatives are shaping the future of Bloom syndrome care and advocacy, and learn how you can actively contribute and get involved in shaping the future of Bloom syndrome research and support efforts.

The Power of Choice: Thriving with Bloom Syndrome

Presented by: Ron Squire LCSW, Squire Counseling

When faced with circumstances out of our control, we still have a choice: what stand do we make? There is power and peace that can still be obtained in the face of our challenges, based on how we choose to live. This session will address how to make philosophical choices that not only help us to live with Bloom Syndrome, but to thrive.

Bloom Syndrome and Cancer: Knowledge is Power!

Presented by: Vivian Chang MD MS, University of California, Los Angeles

With special video appearances by Lorne Yasbin, Todd Prince and Zak Rogers

Bloom syndrome is associated with an increased risk of cancer and patients with Bloom syndrome may experience more side effects from traditional cancer treatments compared to patients without Bloom syndrome. We will review common cancer terminology as well as what we currently know about cancer and Bloom syndrome. We will also discuss cancer surveillance

2024 Bloom Syndrome Patient & Family Conference

strategies and opportunities to contribute to research in this area. Interviews from Bloom syndrome patients who have fought cancer will be shared throughout this presentation.

The UK Bloom Syndrome National Service: A Model of Specialist Care

Presented by:

Shehla Mohammed MD, Rare Diseases Centre at St Thomas Hospital, London

Stefan Meyer MD, Royal Manchester Children's Hospital

Rui Santos MD, Evelina London Children's Hospital

Leza Wightman, Bloom syndrome parent

The Bloom syndrome national service was established in 2023 as part of a Rare Disease Clinical Network. We will share an overview of our specialist multidisciplinary clinics, the development of integrated care pathways alongside a be-spoke management plan for patients and the key role of a dedicated specialist nursing team. We will share other clinical observations and challenges whilst reflecting on future plans. One of our parents will kindly provide feedback from the family perspective.

A Roadmap for Living with Bloom Syndrome

Presented by:

Paula Hesch, Bloom syndrome parent

Mary Beth Campbell PhD, Chair of BSA Board of Directors

This session takes you on a journey of the life of a person with Bloom syndrome. The presentation will offer a timeline of Jason Hesch's life achievements while dealing with the challenges of having a rare disease. This session aims to inspire you to look for the positive aspects of raising a child or growing up with Bloom syndrome. At the end of the session, you will learn about a survey/questionnaire that is being distributed to families who have a member with Bloom syndrome who has experienced cancer, with the goal of developing better care when cancer strikes.

BSA Olympics!

Facilitated by: Talon Webb, Bloom syndrome parent

Attendees are invited to participate in outdoor activities as a fun way to end the day. There will be something for everyone, from competing in team events, to judging and spectating.

Rain plan: Event will be cancelled; attendees are invited to go swimming in the hotel's indoor pool or otherwise enjoy time together, instead.

Small Group Topical Discussions

Choose your own adventure! Small group discussions offered concurrently in two 55-min sessions separated by a 10-min transition break. Each discussion group provides an opportunity for patients and families to ask questions and share experiences about the discussion topic, and will be facilitated by a clinician or parent, as appropriate to the topic. Topics are:

Parenting Young Children with Bloom Syndrome

Facilitated by: Wes Campbell

2024 Bloom Syndrome Patient & Family Conference

Parenting Teens and Tweens with Bloom Syndrome

Facilitated by: Anne Marie and Henri van den Hurk

Living as an Adult with Bloom Syndrome

Facilitated by: Victoria Warren

Grieving the Loss of a Loved One

Facilitated by: Paula Hesch

Infection and Immunity Concerns in Bloom Syndrome

Facilitated by: Nicole Kucine MD

Growth and Fertility Concerns in Bloom Syndrome

Facilitated by: Christopher Cunniff MD

Other Health Concerns in Bloom Syndrome

Facilitated by: Shehla Mohammed MD and Stefan Meyer MD

Advancements in Research: Towards a Patient-Focused Agenda

Presented by:

Chris Brünger, BSA-Japan and Research Roundtable Organizer

Mary Beth Campbell PhD, Chair, BSA Board of Directors

Nathan Ellis PhD, University of Arizona

Representatives from the Research Roundtable

In this interactive session, participants from the Research Roundtable will provide the latest Bloom Syndrome research updates, discuss a patient-focused research agenda to drive future activities, and talk about how you are a critical component in research. Join us to engage directly and shape the future of Bloom syndrome research!

Closing Remarks

Presented by: Christopher Cunniff MD

Dr. Cunniff will conclude the formal conference activities with thank you's and a request to complete the online conference survey.

Afternoon Activities – On Your Own

Make a plan with other families to do something fun in the Frankfurt area or venture out on your own. Suggested activities will be provided by the BSA.

2024 Bloom Syndrome Patient & Family Conference

Conference Presenters



Chris Brünger, MD

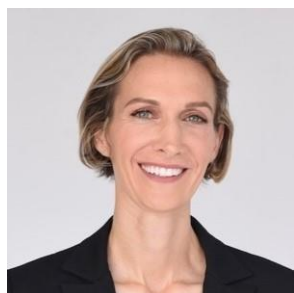
Chris Brünger, MD, German national, long-term resident in Japan, member of Japanese Bloom Syndrome family through my wife. BSA Japan coordinator.

Internist (focus GI oncology, Essen University, Germany; Fujita Health University, Nagoya; Keio University, Tokyo) and pharmaceutical physician with international drug development experience in big Pharma (Schering AG, Pharmacia), consulting for Pharma/Biotech and for NPO Drugs for Neglected Diseases initiative, Geneva.



Vivian Chang, MD

Vivian Y. Chang is a pediatric hematologist-oncologist at University of California, Los Angeles, Mattel Childrens Hospital. She established the first multidisciplinary genomics clinic for pediatric cancer predisposition in 2012 and specializes in taking care of patients with suspected or identified cancer predisposition syndromes. This translational clinic provides opportunities and access to research through biobanking and various research trials for targeted therapies, new sequencing technology, and improved surveillance. Her lab research focuses on hematopoietic stem cell maintenance and regeneration, wide applicability in ameliorating side effects from chemotherapy and radiation, improving bone marrow transplantation, and potentially preventing development of leukemia.



Mary Beth Campbell, PhD

Mary Beth Campbell currently serves as the Chair of the Bloom Syndrome Association's Board of Directors. She has served on the Board since 2018, and has been actively involved in several committees. In 2017, Mary Beth and Wes Campbell organized a workshop focused on Bloom syndrome; they, along with the other families that participated, subsequently published a paper outlining research priorities from the patient community perspective. Mary Beth received her Ph.D. in Applied Physics from Harvard University, where she was a National Defense Science and Engineering Fellow.

2024 Bloom Syndrome Patient & Family Conference



Chris Cunniff, MD

Dr. Christopher Cunniff is a board-certified Pediatrician and Medical Geneticist and is the Chief of the Division of Medical Genetics at Weill Cornell Medical College in New York. He has been a practicing medical geneticist for over 25 years and is currently Professor of Pediatrics and Co-Director of the Bloom Syndrome Registry. He has served in leadership roles in medical genetics as Chair of the Committee on Genetics of the American Academy of Pediatrics, as a member of the Board of Directors of the American College of Medical Genetics, and as President of the American Board of Medical Genetics. In 2015 he assumed leadership of the Bloom Syndrome Registry, which maintains medical information on over 275 persons with Bloom syndrome, as well as samples from over half of registrants. Working with other experts on Bloom syndrome, he has authored clinical care recommendations for people with Bloom syndrome, which are to appear soon in the American Journal of Medical Genetics. He is actively engaged in additional Bloom Syndrome investigations on feeding and nutrition concerns, cancer onset and treatment, sensitivity to ultraviolet and ionizing radiation, and the genetic changes seen in cancer in people with Bloom syndrome. He is very pleased to be working together with participants and speakers at this conference to understand the medical and social needs of people with Bloom's Syndrome, to increase and share knowledge, and to plan for the future.



Nathan Ellis, PhD

Nathan Ellis is a Professor of Cellular and Molecular Medicine at the University of Arizona and a program leader in the University of Arizona Cancer Center. He trained in human molecular genetics at the University of Washington in Seattle and the Imperial Cancer Research Fund in London. He has previously held academic positions at the New York Blood Center and Memorial Sloan-Kettering Cancer Center in New York and University of Chicago and University of Illinois at Chicago. He studies genetic mechanisms regulating homologous recombination during DNA replication and dysregulation of the WNT signaling pathway in early-onset colorectal cancer. He is part of a large group of researchers at Arizona developing cellular models of neoplasia that better inform outcomes in drug development.

2024 Bloom Syndrome Patient & Family Conference



Paula Hesch

Paula is a longstanding member of the Bloom syndrome community and the mother of Jason Hesch, who had Bloom syndrome and passed away in 2023. Paula has been leading an initiative with the BSA to gather insights and experiences from those who have battled Bloom syndrome cancers to better understand the challenges faced by those with cancer, help identify areas where support and resources are needed most, and develop a better understanding of successful Bloom syndrome cancer treatments.



Nicole Kucine, MD

Dr. Nicole Kucine received her training in pediatric hematology/oncology at the combined fellowship program of Weill Cornell Medicine and Memorial Sloan Kettering Cancer Center. She joined the faculty of the Department of Pediatrics of Weill Cornell Medicine in 2011 and is currently an Associate Professor of Clinical Pediatrics. She received a master's degree in Clinical and Translational Investigation in 2015 and is an active clinical researcher in various areas of pediatric hematology and oncology. She took over leadership of the Bloom Syndrome Registry in Spring of 2022.



Stefan Meyer, MD

Dr. Stefan Meyer works as a Honorary Consultant Pediatric Oncologist at the Royal Manchester Children's Hospital, and the Young Oncology Unit/Palatine Treatment Centre at the Chrisite NHS Foundation Trust.

He leads the multidisciplinary care for children with Fanconi anaemia, Bloom syndrome and other Chromosomal Instability Syndromes.

2024 Bloom Syndrome Patient & Family Conference



Shehla Mohammed, MD

Shehla is a paediatric clinical geneticist with 28 years' experience predominantly in rare genetic conditions and in the care of children and families with complex life-limiting disorders. Originally a paediatric intensivist, she undertook further training in Clinical Genetics and was as an ICRF Clinical Research Fellow in Cancer Genetics at Guy's Hospital.

Until 2017, she was Head of Service of the Guy's Regional Genetics Service (SE Thames Regional Clinical and Diagnostic Laboratories) for 20 years.

Shehla has a special interest in translating new technologies into a clinical setting and to enable the successful delivery of multidisciplinary and patient-focused services. With a strong clinical and managerial background, she has successfully advocated for rare diseases and has developed and leads National Highly Specialist Multidisciplinary Services for a number of complex disorders with colleagues from the dedicated Rare Diseases Centre at St Thomas Hospital, London.

She has been the Principal Investigator in Phase III clinical trials and has effectively fostered international collaborations to improve patient outcomes for rare and ultrarare multisystem disorders.

She has been involved with a number of professional bodies. Currently, she is a member of the Highly Specialised Technologies Evaluation Committee at NICE (which assesses novel therapies for rare and ultra rare disorders for implementation in the NHS), a member of the England Rare Disease Framework Working group (Sept 2021- to date), an Associate of the PHG Foundation at Cambridge and a Trustee for a number of patient support groups.



Ron Squire, LCSW

Ron became interested in the field of mental health after a life-altering hiking accident that left him partially paralyzed. This incident greatly impacted him for the good and gave him unique insight into helping others through their challenges. He is insatiably curious and his constant reading is an asset to his work. Ron's love of history, philosophy, neuroscience, the outdoors, and well-timed humor helps his clients work towards their goals. Whether it's difficult life transitions,

mental health battles, or goal setting, Ron is here for you and your loved ones. He genuinely considers it his life's work.

Throughout his career, he has worked with teens, families, couples, and individuals. He also has extensive knowledge and expertise in working with individuals on the Autism Spectrum. Ron understands the complexity that can exist in the issues we face. If you are experiencing difficult life transitions, existential turmoil, trauma, anxiety, depression, grief, addictions, or family conflict, Ron is highly skilled in treating these areas of life that feel insurmountable at times.

2024 Bloom Syndrome Patient & Family Conference



Leza Wightman

Leza Wightman lives in North Yorkshire, England with her husband James, and two children, George and Olivia. Olivia was diagnosed with Bloom syndrome when she was 18 months old; she is now 16 years old. Leza has been an active member of the Bloom community for approximately ten years and this is her fourth conference attendance.

2024 Bloom Syndrome Patient & Family Conference

Thanks to Our 2024 Conference Volunteers!



Mary Beth Campbell



Sylvia Campbell



Wes Campbell



Jodie Madry



Jochen Obermeier



Tanja Obermeier



Eileen Rosenthal



Rachel Rosenthal



Mary Treder



Anne Marie van den Hurk



Henri van den Hurk



Victoria Warren



Anne Webb



Talon Webb



Susan Zaslaw

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BSA Leadership

Board of Directors

Chair: Mary Beth Campbell

Vice Chair: Mary Treder

Secretary: Lorne Yasbin

Treasurer: Talon Webb

General Members: Tanja Obermeier, Victoria Warren

Committee Chairs

Communications and Marketing: Mary Treder

Community Engagement: Lorne Yasbin

Conference and Events: Eileen Rosenthal

Fundraising: Victoria Warren

Medical-Scientific Advisory Board Members

Christopher Cunniff, MD (Chair)

Vivian Chang, MD

Nathan Ellis, PhD

Joanna Groden, PhD

Nicole Kucine, MD

Stefan Meyer, MD

Edith Schussler, MD

Maria G. Vogiatzi, MD

Lisa Wang, MD

2024 Bloom Syndrome Patient & Family Conference

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2024 Bloom Syndrome Patient & Family Conference

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2024 Bloom Syndrome Patient & Family Conference

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2024 Bloom Syndrome Patient & Family Conference

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* Conference presenters and facilitators