



**2022 Bloom Syndrome  
Patient & Family Conference**

August 5-7  
Chicago, Illinois, USA

Conference Program

# 2022 Bloom Syndrome Patient & Family Conference

We would like to thank our sponsors for their generous contributions and for their hard work in making this meeting possible.



## Bloom Syndrome Registry



*And many donations made by BSA members,  
their families and friends!*

# 2022 Bloom Syndrome Patient & Family Conference



Welcome to the 2022 Bloom Syndrome Patient & Family Conference. We are excited to have you attend, and we 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 members' health and well-being. We hope that this conference will bring a new level of connection for people with Bloom syndrome and their families, friends and health care teams. We are stronger together!

## Conference Planning Group

Mary Beth Campbell  
Chris Cunniff  
Stefan Meyer  
Joe Ryan  
Susan Zaslav (Chair)

## Event Management Team

Tricia Burke  
Sylvia Campbell  
Eileen Rosenthal  
Annie Webb  
Susan Zaslav

# 2022 Bloom Syndrome Patient & Family Conference

## Schedule & Agenda

Unless otherwise noted, all sessions will be in Salon Meeting Rooms C-D-E-F.

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### Friday, 8/5/22

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|-----------------|---|
| 5:00pm – 8:00pm | Conference Check-In<br>Location: Atrium Grove (Level 2)                               |
| 5:30pm – 7:30pm | Welcome Reception<br>Location: Atrium Grove (Level 2)                                 |
| 5:30pm – 7:30pm | Childcare/Kids' Activities Providers Meet & Greet<br>Location: Atrium Grove (Level 2) |
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### Saturday, 8/6/22, Morning

- |                   |   |
|-------------------|---|
| 7:30am – 8:30am   | Conference Check-In<br>Location: Salon Rooms C-D-E-F (Level 1)  |
| 8:00am – 11:30am  | Childcare/Kids' Activities<br>Location: Salon Rooms A-B (Level 1)   |
| 8:30am – 9:00am   | Conference Welcome<br><i>Presenters: Mary Beth Campbell, Susan Zaslav</i>   |
| 9:00am – 10:00am  | Getting to Know You! Community Introductions<br><i>Facilitator: Lorne Yasbin</i>  |
| 10:00am – 10:30am | Networking/Refreshment Break  |
| 10:30am – 11:30am | Raising a Child with Bloom Syndrome: Being an Effective Advocate –<br>Panel Discussion<br><i>Moderator: Jodie Madry</i> |
| 11:30am – 12:00pm | Group Photo<br>Location: To be announced  |
| 12:00pm – 1:00pm  | Buffet Lunch<br>Location: Atrium (Level 2)  |

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### Saturday, 8/6/22, Afternoon

- 1:00pm – 5:00pm      Childcare/Kids' Activities  
Location: Salon Rooms A-B (Level 1)
- 1:00pm – 2:00pm      Growing Up with Bloom Syndrome: When Your Age Doesn't Match  
Your Size – Panel Discussion  
*Moderator: Leslie Ryan*
- 2:00pm – 3:00pm      Stronger Together: Teaming Up Against Cancer  
*Presenters: Vivian Chang, MD; Lisa Wang, MD*
- 3:00pm – 3:30pm      Networking/Refreshment Break
- 3:30pm – 4:15pm      Bloom Syndrome Research Updates  
*Presenters: Nathan Ellis, PhD; Joanna Groden, PhD;  
Jalees Rehman, MD*
- 4:15pm – 5:00pm      Bloom Syndrome Registry Update  
*Presenter: Christopher Cunniff, MD*
- 5:00pm – 6:00pm      Free time
- 6:00pm – 8:00pm      Group Dinner  
Location: Five Roses Pub, 5509 Park Pl, Rosemont  
Within walking distance of the hotel
- 8:00pm – 10:00pm      Young Adult Get-Together (21 years and older)  
*Organizer: Lexi Ryan*  
Location: Gibsons Bar & Steakhouse, 5464 N River Rd, Rosemont
- 8:00pm – 10:00pm      Teen/Pre-Teen Movie Night  
*Chaperones: Talon and Annie Webb, Susan Zaslav*  
Location: Boardroom East (Level 1)

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### Sunday, 8/7/22

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|-------------------|--|
| 8:00am – 12:00pm  | Childcare/Kids' Activities<br>Location: Salon Rooms A-B (Level 1)  |
| 8:30am – 9:15am   | Managing Immunodeficiency in Bloom Syndrome<br><i>Presenter: Edith Schussler, MD</i>   |
| 9:15am – 10:15am  | BSA Update: Building for the Future<br><i>Presenters: Mary Beth Campbell, Leslie Ryan, Talon Webb, Lorne Yasbin, Susan Zaslav</i>  |
| 10:15am – 10:45am | Networking/Refreshment Break   |
| 10:45am – 11:30am | What's On Your Mind? – moderated attendee discussion<br><i>Moderator: Talon Webb</i>   |
| 11:30am – 11:45am | Closing Remarks<br><i>Presenter: Mary Beth Campbell</i>  |
| 11:45am – 12:00pm | Conference Survey<br><i>Facilitator: Susan Zaslav</i>  |
| 12:00pm – 1:00pm  | Lunch (box lunches)<br>Location: Atrium Grove (Level 2)  |
| 1:00pm – 1:30pm   | Free time  |
| 1:30pm – 5:00pm   | Family Recreation Activity (optional)<br>Location: Urban Air Adventure and Trampoline Park<br>7401 West 25th St, North Riverside<br>Bus transportation will be provided to/from Urban Air. |

# 2022 Bloom Syndrome Patient & Family Conference

## Session Descriptions

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Note: Copies of the speaker's presentations and session recordings will be made available on the BSA website after the conference.

### Conference Welcome

Presentation by Mary Beth Cambell and Susan Zaslav (recorded)

Mary Beth and Susan will kick off the conference with some welcome remarks and conference logistics.

### Getting to Know You! Community Introductions

Group activity led Lorne Yasbin (not recorded)

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

### Raising a Child with Bloom Syndrome: Being an Effective Advocate

Panel Discussion led by Jodie Madry (not recorded)

Panelists: Wes Campbell, Paula Hesch, Eileen Rosenthal, Joe Ryan

Jodie will start off this session with a series of prepared questions for the panelists, then open the discussion to questions from the audience.

### Growing Up with Bloom Syndrome: When Your Age Doesn't Match Your Size

Panel discussion led by Leslie Ryan (not recorded)

Panelists: Izzy Madry, Zach Rogers, Rachel Rosenthal, Christian Ryan, Lexi Ryan and Victoria Warren

Leslie will begin with a series of prepared questions for the panelists, then ask the audience for their questions.

### Stronger Together: Teaming Up Against Cancer

Presentation by Vivian Chang, MD and Lisa Wang, MD (recorded)

Drs. Chang and Wang will provide an overview of cancer and what's known about cancer in Bloom syndrome. This overview will be followed by a discussion of what to do if you receive a cancer diagnosis and lessons we can learn from another rare disease similar to Bloom syndrome, Rothmund-Thomson syndrome.

# 2022 Bloom Syndrome Patient & Family Conference

## Session Descriptions

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### Bloom Syndrome Research Update

Presentation by Nathan Ellis, PhD; Joanna Groden, PhD; and Jalees Rehman, MD (recorded)

What are the opportunities at the interface between new technologies and Bloom syndrome for generating new knowledge and developing new treatments? Recent advances in generating and analyzing high-dimensional genomic data combined with cutting-edge cell culturing methods and precision mouse models promise major steps forward in understanding cell physiology, cancer biology, and organismal development in Bloom syndrome. These models set the stage for translational of research findings in the laboratory to clinical trials.

### Bloom Syndrome Registry Update

Presentation by Christopher Cunniff, MD (recorded)

Dr. Cunniff will talk about what the Registry does, what it's been up to, and its plans for the future. He will also present a video from the new Registry Director, Dr. Nicole Kucine.

### Managing Immunodeficiency in Bloom Syndrome

Presentation by Edith Schussler, MD (recorded)

Dr. Schussler will provide a brief overview of the immune system, then discuss immune dysregulation in Bloom syndrome and how immune issues in Bloom syndrome present, are evaluated, and treated.

### BSA Update: Building for the Future

Presentation by Mary Beth Campbell, Leslie Ryan, Talon Webb, Lorne Yasbin, Susan Zaslav (recorded)

Mary Beth, members of the BSA Board of Directors, and Committee Chairs will provide an overview of what the BSA is and does, and how you can get involved.

### What's On Your Mind?

Group discussion facilitated by Talon Webb (recorded)

This session is an opportunity to ask any questions you still have at the end of the conference. Talon will direct your questions to the appropriate member of the BSA Board of Directors or Medical-Scientific Advisory Board.

### Closing Remarks

Presentation by Mary Beth Campbell (recorded)

Mary Beth will conclude the formal conference activities with some parting words.



# 2022 Bloom Syndrome Patient & Family Conference

## Conference Survey

Facilitated by Susan Zaslav (not recorded)

Susan will ask you to complete a conference survey to help us make the next conference even better!

# 2022 Bloom Syndrome Patient & Family Conference

## Conference Presenters

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### **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's 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's Syndrome Registry, which maintains medical information on over 275 persons with Bloom's Syndrome, as well as samples from over half of registrants. Working with other experts on Bloom's Syndrome, he has authored clinical care recommendations for people with Bloom's Syndrome, which are to appear soon in the American Journal of Medical Genetics. He is actively engaged in additional Bloom's 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's 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**



Dr. Nathan Ellis is a cancer geneticist in the Department of Cellular and Molecular Medicine at the University of Arizona. He serves as Program Director of the Cancer Biology Program in the University of Arizona Cancer Center and Director of the Genetics graduate program. Dr. Ellis was born and raised in New York City, beginning his scientific career in somatic cell genetics and studying gene regulation, sex determination, and mammalian development. In 1990, he joined the New York Blood Center as an Assistant Member, where in collaboration with James German and Joanna Groden he characterized the molecular genetics of the gene mutated in Bloom's syndrome BLM. In 1997, Dr. Ellis took a position in the Department of Human Genetics at Memorial Sloan-Kettering Cancer Center, continuing studies of molecular mechanisms underlying genomic instability and the cancer genetic epidemiology and population genetics of colorectal cancer. He has since held positions at the University of Chicago and the University of Illinois at Chicago studying cancer health disparities and the relationship between genetic risk factors and environmental factors in colorectal carcinogenesis. He continues to study molecular mechanisms underlying genomic instability in Bloom's syndrome with the aspiration to develop better treatment options for persons with the syndrome who develop cancer.

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## Conference Presenters

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### Joanna Groden, PhD

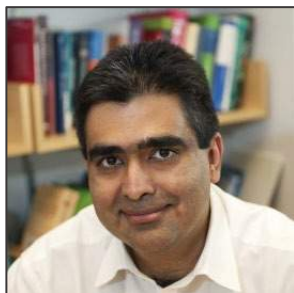


Dr. Joanna Groden is a human cancer geneticist who is internationally recognized for her research in identifying key genetic causes of colon cancer and other inherited cancers through the identification and characterization of two human disease genes. With numerous publications and patents, Dr. Groden was elected as a Fellow of the American Association for the Advancement of Science (AAAS) and a Fellow of the American Gastroenterological Association. She currently serves as the Vice Chancellor for Research at the University of Illinois

Chicago, where she is also a Professor in the College of Medicine Department of Biochemistry and Molecular Genetics.

Dr. Groden joined Dr. James German's Laboratory of Human Genetics at The New York Blood Center in 1978 after completing her BA degree in Biology at Middlebury College, continuing his tradition of hiring Middlebury graduates. After working with Dr. David Bloom, Dr. German and the families of those affected by Bloom's syndrome, she was inspired to learn more about how the chromosome breakage syndromes led to cancer predisposition. She enrolled in the nearby Cornell University Graduate School of Medical Sciences, affiliated with the then Cornell University Medical College, and received a PhD in Cell Biology and Genetics. Dr. Groden completed a postdoctoral fellowship in the Department of Human Genetics/Howard Hughes Medical Institute at the University of Utah. In 1995 and in collaboration with Dr. German and Dr. Nathan Ellis, she was part of the team to identify the BLM gene and characterize the molecular genetics of the gene mutated in Bloom's syndrome.

### Jalees Rehman, MD



Dr. Jalees Rehman is a professor of medicine and pharmacology and regenerative medicine at the UIC College of Medicine. His laboratory studies how organs and blood vessels are injured by bacterial or viral infections. His research is finding ways to dampen excessive inflammation and activate tissue regeneration so that organs recover.

Rehman's most recent research shows how blood vessels in organs differ from each other and why the lung blood vessels are especially vulnerable to severe injury, such as what is seen in patients with severe COVID-19. His research group is also using machine learning and deep learning tools to understand the genes that regulate inflammation, injury and repair.

# 2022 Bloom Syndrome Patient & Family Conference

## Conference Presenters

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### **Edith Schussler, MD**



Dr. Edith Schussler is a board-certified Allergist and Immunologist and an Assistant Professor of Pediatrics at Weill Cornell Medical College. A native New Yorker, Dr. Schussler received her undergraduate degree at the University of California Berkeley, before completing premedical studies at Harvard University. She returned to New York to attend the Icahn School of Medicine, where she also completed her residency in pediatrics and fellowship in adult and pediatric Allergy and Immunology. Dr. Schussler received grants from the Jeffery Modell Foundation and the United States Immunodeficiency Network to support her fellowship research. Over the past year, she has presented her immunology research at the European Society for Immunodeficiencies, The Clinical Immunology Society, the American Academy of Allergy Asthma & Immunology, and the American College of Allergy Asthma & Immunology. She has published on immune dysregulation in Gaucher disease, allergy to Botulinum antitoxin, food allergy and genetic immune deficiency. She is an active member of the education committee for the New York Asthma Allergy Society, the Early Career Immunologist Committee of the Clinical Immunology Society, and the Anaphylaxis Committee of the American Academy of Allergy Asthma & Immunology.

# 2022 Bloom Syndrome Patient & Family Conference

## BSA Board of Directors and Committee Members

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### Board of Directors

Chair: Mary Beth Campbell

Vice Chair: Talon Webb

Secretary: Lorne Yasbin

Treasurer: Tricia Burke

General Members: Stefan Meyer, Susan Zaslaw

### Committee Members

Communications and Marketing:

Leslie Ryan (Chair), Lexi Ryan, Annie Webb, Susan Zaslaw (Board Liaison)

Community Engagement:

Lorne Yasbin (Chair), Skeifa Burke, Mary Treder, Paul Zaslaw

Conference and Events:

Susan Zaslaw (Chair), Chris Cunniff, Stefan Meyer, Joe Ryan

Fundraising:

Mary Beth Campbell (Chair), Tricia Burke, Debbie James, Renee Reed, Melanie Yasbin



# 2022 Bloom Syndrome Patient & Family Conference

## Conference Attendees

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Elwyn Castle	Colorado, USA	
Arthur Castle	Colorado, USA	
Ambrose Castle	Colorado, USA	
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# 2022 Bloom Syndrome Patient & Family Conference

## Conference Attendees

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## Conference Attendees

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Max Webb	Utah, USA	



# 2022 Bloom Syndrome Patient & Family Conference

## Conference Attendees

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James Wightman	North Yorkshire, UK	
George Wightman	North Yorkshire, UK	
Mary Yagle	Arizona, USA	
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Melanie Yasbin	Maryland, USA	yasbin@verizon.net
Brady Yasbin	Maryland, USA	
Susan Zaslaw	New Hampshire, USA	smzaslaw@gmail.com

\*Speaker