



## *Bloom's Connect*

**First Annual Conference  
May 27-28, 2008**

**University of Illinois at Chicago  
1640 West Roosevelt Road  
Chicago, Illinois 60608**

**For registration information, contact:**

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# Agenda

## DAY ONE

**8:00 am Registration**

**8:30 am Welcome**

**8:45 am Breakout Sessions**

*These sessions will allow participants to formally meet as a group of parents, siblings, and people with Bloom's Syndrome to talk and share experiences with others like themselves.*

### **Breakout Session A: Look Out World, Here We Come!**

Session for adults with Bloom's Syndrome: Share experiences about college, work, and the social scene. We discuss these topics without parents, families, or medical professionals present.

### **Breakout Session B: This Is Not What I Planned For — My Child Was Diagnosed With Bloom's Syndrome**

Session for parents of people with Bloom's Syndrome: Share stories, fears, worries, successes, struggles, and laughs with other parents.

### **Breakout Session C: Hey You Look Like Me!**

Session for school-age people with Bloom's Syndrome: Share experiences about school, friends, teasing, and what's important in life. (5 attendees minimum to run session.)

### **Breakout Session D: When My Sibling Is Different**

Session for siblings of people with Bloom's Syndrome: Share stories, fears, worries, frustrations, and giggles with others who have a sibling with Bloom's Syndrome. (5 attendees minimum to run session.)

**9:00 am Break**

**9:05 am      Breakouts Continue**

*At the conclusion of this session all groups will come together in a Bloom's Syndrome community-building exercise.*

**9:45 am      Coffee Break**

**10:00 am      Session 1**

**Nutrition: Sense and Sensibility in Bloom's Syndrome**

People with Bloom's Syndrome often have different sensory perceptions of taste and touch. This session will explore some practical solutions to everyday sensory experiences surrounding food and drink. Issues discussed will range from practical methods of "getting through a feeding", to learning how to gauge appropriate portion sizes, to ensuring good nutrition and balanced diet while being sensitive to sensory disturbances, to dealing with reflux and other GI conditions.

**11:00 am      Break**

**11:05 am      Session 2**

**Up to the Gills: A Practical Discussion of How the Stress of Medical Crises Can Try Personal Relationships**

This session shifts focus to the caregivers among us who will learn positive coping strategies for dealing with medical crises. We also learn how to let others assist us as people with BS.

**12:00 pm      Lunch**

**1:30 pm      Session 3**

**Wearing the Inside, Out: When Self-Esteem Trumps Size - I Am Who I Am**

Successful navigation of the world with Bloom's Syndrome is based upon positive self-image, self-esteem, and identity. Tips and tools for achieving this goal will be shared. Practical solutions to everyday challenges will be offered.

**2:30 pm      Break**

**2:45 pm      Session 4**

**Building Lasting Friendships**

Today's social relationships are often based on a 30-second first impression. This session will provide tips and tools for making a positive first impression regardless of height, weight, photosensitivity break-outs, and surgical scars. Socialization issues for children in daycare and school will be addressed. Parents will explore social acceptance and support in the community after acquiring a diagnosis of BS for their child. Parents will learn how to help their child with BS foster meaningful, lasting relationships. Practical skills for building lasting and meaningful relationships in school, work, and social settings will be addressed with regards to our adult "Bloomies."

**3:45 pm      Break**

**4:00 pm      Session 5**

**Individualized Education Plans /  
Individualized Employment Plans**

After the home, school is the most formative institution in a person's life. No matter who our children are, they have the right to be educated to grow up feeling confident about themselves, be respectful and tolerant of others, and plan to be the best lawyer, scientist, artist that we can be. Research shows that academics improve with increased support, across demographics. Students with Bloom's Syndrome and their families will explore ways to be the best they can be in school and plan well-ahead for the world of higher education and the world of work. For those already looking at employment, we will explore "futures planning" based on desires, needs, and skills that make for solid job matches.

**5:00 pm      Break for the Day**

**9:30 am      Session 1**

**Speak Up, Ask Questions, Become Your Own Expert**

Whether you are a parent working with daycare, the school system, the medical establishment, social service system, your workplace; or an adult with Bloom's Syndrome working within any of these systems, or the adoption system, this session will provide a framework for asking questions and being assertive in order to achieve your goal.

**10:30 am      Break**

**11:00 am      Session 2**

**The Future of "Bloomsconnect.org"**

It is time for our community to generate a comprehensive plan for moving forward as a community. We will develop a strategy for continuing and enhancing our Bloom's Syndrome support group.

**12:00 pm      Lunch**

**1:30 pm      Session 3**

**Panel Discussion**

Two people with Bloom's Syndrome, a sibling, and a parent will answer pre-submitted questions and field additional questions from the audience.

**2:30 pm      Break**

**2:45 pm      Session 4**

**Community Resources**

Local, National, and International resources for enhancing the lives of people with Bloom's Syndrome will be showcased.

**3:45 pm      Break**

**4:00 pm      Closing Session**

**4:30 pm      End of Conference**

**Jewish Family & Children's Services**  
**10954 Schuetz Road**  
**St. Louis, MO 63146**  
**(314) 993-1000**

## **Frequently Asked Questions: Bloom's Syndrome Conference**

### **1. Who should come to "The Bloom's Connection: Unraveling the Mystery" Conference?**

People with Bloom's Syndrome, parents of people with Bloom's Syndrome, siblings of people with Bloom's Syndrome. Treating physicians are encouraged to attend as well.

### **2. Should I bring my children?**

This is a personal decision that should be made by each family. We are working very hard to make this experience family friendly. There will be childcare available during conference sessions. Activities available to the children will range from music, art, story-time, and free play. Children with Bloom's Syndrome and their siblings are all welcome. There will be certain sessions specific to those who are individuals with Bloom's and those who are siblings.

### **3. What topics will be covered?**

While the primary focus of the conference will be to allow families affected by Bloom's Syndrome to meet each other and have the opportunity to share life experiences and tips for successful living, we also have the incredible opportunity to share tips and tools for getting through day-to-day activities and integrating fully into our communities. We will be providing "best practices" gleaned from several years of research in the wider community regarding coping strategies, self-esteem, and identity which has been shown to follow similar patterns as physical development. Often we focus so intently on the medical components of Bloom's Syndrome, that we forget to pay attention to living our lives with the best quality of life possible. With these sessions we can begin to open the door to better, more full lives.

### **4. Who are the speakers?**

Our speakers are a group of world-renowned subject-matter experts in the topics they are presenting. There will be an adult male of short stature speaking about the experience of being a short adult male. We will have a woman with a significant disAbility speaking about forming lasting relationships when living in a world of first impressions. There will be a woman with a low incidence medical condition talking about learning how to be your own expert when working with a medical field that has limited knowledge of your condition. A woman devoting her life to working with people around nutrition, healthy eating, and various GI conditions will be sharing her knowledge with us. There will also be a pastoral counselor who works with families in the medical setting who will facilitate a few of our sessions. The children's sessions will be supervised by knowledgeable, capable staff who are used to working with individuals with and without medical conditions.

**5. Why are there no Dr.'s speaking?**

Although we have offered to have certain physicians speak at the conference, several facts emerged:

- A. Physicians are looking for the same answers we are.
- B. The "Bloom's Connect" Support Group was established to fill a niche that has not yet been addressed: the social aspects of the condition and peer support. Staying true to this mission, we have stuck to what we know best—how to improve the quality of our lives. We have full confidence that the medical community will work to answer our medical questions and concerns as is their mission.
- C. We hope this conference will be just the beginning of a new chapter in the lives of people with Bloom's Syndrome. We hope this conference will raise additional questions and areas for research that can be passed along to the medical community to focus on in our lifetime.

**6. What if I do not speak English well?**

We are arranging for foreign language interpreting for both the adults and the children.

**7. Will there be childcare?**

Yes. There will be childcare available during conference session hours.

**8. Will there be any record kept of this conference?**

Yes. We will be videotaping (with participants' consent) the conference, with the exception of the break-out sessions in order that conference participants can get comfortable with each other.

**9. What if I need financial assistance to attend the conference?**

We are attempting to raise money to assist those who need a little boost in order to attend. We encourage you to let us know if you need assistance so we can set fund-raising goals appropriately. While there are no guarantees, we are working hard to make this a reality for any who wish to take advantage of it.

In addition, we will be happy to assist you in finding as many local resources that you can approach to assist you in coming to a conference of this kind.



**10. What other projects is "Bloom's Connect" involved in?**

Currently we are putting together an event for parents who have not yet disclosed to their child that they have Bloom's Syndrome. It will feature a Child Life Specialist who works in the hospital setting to help parents plan for what, how, and when to disclose to their child. Emphasis will be placed on the developmental level of the child, family dynamics, and medical need. The fact that disclosure is a process and not just a one-time event will also be addressed.

In the future, "Bloom's Connect" is planning to host an event for both parents and adult Bloomies on pain management. Many with Bloom's report having a sensitivity to either cold or heat which often manifests itself as a pain sensation. Many report that this affects mood, stamina, and performance. Many parents report that their child has difficulty wearing certain materials, getting through feedings, and getting through bath-time. While we may not yet have a scientific understanding of the medical event causing this sensation, there are methods of pain control that can be shared amongst the community that can improve our quality of life.

The Bloom's Syndrome Foundation  
and  
The Bloom's Syndrome Workshop

INVITE BLOOM'S CONNECT  
TO

*A Conversation Concerning Bloom's Syndrome*

James German, M.D. and Maureen Sanz, Ph.D.  
Registrars, The Bloom's Syndrome Registry  
Weill Medical College of Cornell University  
New York City

and

Richard Gladstein  
Director, The Bloom's Syndrome Foundation  
Los Angeles

**Tuesday, May 27, 2008**

**5:30-7:00 p.m.**

Board Room, 6<sup>th</sup> floor  
Gleacher Center  
450 North Cityfront Plaza Drive  
Chicago

RSVP and inquiries: Nathan Ellis, Ph.D. at 773/702-7868 or [naellis@uchicago.edu](mailto:naellis@uchicago.edu)