



**Bloom's Syndrome Association**

May 22, 2014

Dear First-Time Visitors to the BSA Website,

Welcome!

After many years in the making, the website of the Bloom's Syndrome Association is ready for service. The Association is dedicated to the wellbeing of individuals, families, and friends affected by Bloom's syndrome. We are bound by common experiences, with an opportunity in numbers to inform research and boost our understanding of this rare genetic disorder. We hope to improve the quality of life of persons diagnosed with Bloom's syndrome, provide practical information for parents and other advocates, increase public awareness of the syndrome, and raise funds to support basic research and clinical investigations.

The website is divided into public and private areas, with the majority of educational content viewable by all. Members of the BSA will have exclusive access to additional content and features, including journal articles, photo galleries, forums, surveys, member profiles, networking options, and more. For those with a direct connection to or otherwise interested in Bloom's syndrome, we are eager to gain your support and encourage you to join the Association and participate in its mission.

Currently, there are no dues or eligibility requirements to become a member of the BSA. As the Association matures, we anticipate increasing interactions between families and stakeholders, developing new services and functions for the website (e.g., special-interest groups, member-run blogs and forums, podcasts, wikis, new and improved content, etc.), collecting more information about our constituency, and polling ourselves about how to better achieve our goals.

This website is a work-in-progress, evolving to meet the needs and serve the interests of the international Bloom's syndrome community. While the majority of resources currently listed are U.S.-based, the BSA plans to provide, over time, a more global perspective. Getting here has been a long process from modest beginnings, but our will is strong and our potential is great. Overall, we are driven by our love of family and our hopes for the future. We invite you to explore the BSA website and respond with your comments and suggestions.

Sincerely,

Paul Zaslaw, President  
Bloom's Syndrome Association, Inc.