CRIBBS Newsletter

October 2026

Sent on behalf of the Marshfield Clinic BBS Center of Excellence Leadership Team

Greetings,

The mission of the Center of Excellence for Bardet-Biedl Syndrome is to enrich the health and quality of life for individuals affected by BBS through compassionate interdisciplinary health care, scientific advancement and community outreach.

The video recordings from the BBS Foundation conference in Washington DC are now available. The playlist can be found at https://www.youtube.com/watch?v=BPvDBnVsoAk&list=PLQKRDdf03AP8. Thanks again to the Race Against Blindness for producing these re For more information about the conference and news from the BBS Foundation please see: Bardet Biedl Syndrome Foundation.

Thank you for your participation in CRIBBS. If you feel you are past due on a follow up interview, please reach out to us at our email address or phone number. We want to hear from you, even if you do not have any health changes to report.

CRIBBS is made possible through funding and partnership with the BBS Foundation.

Contacts Us:

Email:

cribbs@MCRF.MFLDCLIN.EDU

Phone:

1-877-594-3499 (CRIBBS-English)

1-877-998-0018 (CRIBBS-Spanish)

Social Media and Community Connections

BBS Adults Facebook page

This is a place for adults who have BBS. You can connect with others who have similar experiences, support each other and share your journey through life.
https://www.facebook.com/groups/648889312653215

BBS Family Cookbook

The BBS Family Cookbook has lots of healthy and delicious recipes, collected from members of the BBS community. Try them, share them, and tell others about your favorites on the BBS Adults, Families of BBS, and Bardet Biedl Kitchen Facebook pages. Click below to download the BBS Family Cookbook.
https://www.marshfieldclinic.org/mDonate/Documents/BBS-cookbook-latest-1.pdf

Families of Bardet-Biedl Syndrome Facebook page

If you have a family member with BBS, please consider joining this page. You can connect with other families, share information, and know that you're not alone.
https://www.facebook.com/groups/138529479566568/

Or, if you wish to donate to support BBS care and research at Marshfield Clinic, you can also access the cookbook through their giving page:

https://www.marshfieldclinic.org/giving/bbs#C

Imcivree Setmelanotide Support Group

There is a Facebook support group for those using Imcivree. This group includes families with BBS, PCSK1 and LEPR.

https://www.facebook.com/groups/521922353348974/?ref=share_group_link

Groups

Log-in information: Except for the BBS Sports Club (see the Sports Club listing for separate information), all BBS groups will meet on the Marshfield Clinic BBS Zoom site

Join Zoom Meeting

https://us06web.zoom.us/j/87473711833?pwd=vU39E3gPaR6UOOhwLi1LQ5XeRi8bSd.1

You can also join by either a cell phone or landline:

Phone number: 646-931-3860
Alternate phone number: 312-626-6799
Meeting ID: 874 7371 1833

One tap mobile (this is what you can program into your contacts on your cell phone):

6469313860,,87473711833#

3126266799,,87473711833#

BBS Young Adult Support Group: Saturday October 3 and Saturday November 7 at 7:00 pm Central Time

Facilitated by Jordan Smelley, the group meets the first Saturday of every month. This is a group for young adults, both men and women, ages 18 to 29. The purpose of the group is to provide young adults with BBS with a collaborative forum to share their experiences, ideas and resources with one another, as well as to create interpersonal connections. The atmosphere is informal, and topics vary. For more information contact Jordan Smelley at jordan.smelley@gmail.com

BBS Parents Support Group: Friday, October 30 at 7:00 pm Central Time

The BBS parents support group is moderated by Maxie McGlohon. Everyone is invited to join in. The group meets using the Marshfield Clinic Zoom site; see the information above for the login. For more information, contact Maxie at 2themax03@gmail.com

BBS Book Night: Friday, October 9, at 7:30 pm Central Time (We did not meet last month, so we will be reading *The Calamity Club* this month.)

Moderated by Ellyn Hunter. BBS book night meets the first Friday of every month at 7:30 pm Central Time. The book is always available from BARD, and usually from Audible, local libraries, and possibly Bookshare. The group uses the Zoom site for Marshfield Clinic. This month, we will be reading *The Calamity Club,* by Kathryn Stockett. Description: Oxford, Mississippi, 1933. Abandoned by her mother one Christmas Eve, eleven-year-old Meg Lefleur has learned the hard way to rely on no one. Now one of the unadoptable "big girls" at the Lafayette County Orphan Asylum, she fights each day to keep her spirit unbowed. Birdie Calhoun, unmarried and outspoken, has come to Oxford to ask her socialite sister to help the struggling family she's left behind. But as the Depression tightens its grip, Birdie discovers her sister's seemingly charmed life is a tapestry of lies. Then, Birdie encounters Charlie, a woman running low on luck with little left to lose. When their fates -- and Meg's -- converge, Charlie comes up with an audacious plan for them to take control of their lives. But in a place and time where hypocrisy is rife and women's freedom is fragile, even the smallest act of defiance can have dangerous consequences.

BBS Sports Club: Thursdays October 1, 8, 15, 22, and 29 at 5:30 pm Pacific Time.

Facilitated by Bob Stewart, the BBS Sports Club now boasts 12 very active weekly members who log into our Zoom meetings, held each Thursday, 5:30 PM, PST. New members are always welcomed. Our primary purpose is to have fun in a

networking, upbeat, social way. Sports contests are held each week with sports memorabilia prizes.

BBS Sports Club meetings are via Zoom and ordinarily scheduled for Thursday except for holidays. Where a holiday falls on a Thursday or Friday, the meeting is scheduled for Wednesday. Those who are interested in joining the group should contact Bob Stewart at bstewart@yardarmtech.com to get the current Zoom login information.

BBS Women's Group: Sunday, October 25 at 7:00 pm Central Time

This group is an informal gathering for women who have BBS, ages 30 and up. It provides a place for sharing personal experiences, resources, and adaptive strategies, as well as for establishing interpersonal connections. The group meets monthly on a Sunday at 7:00 pm Central Time on the Marshfield Zoom site. For new members, before joining the group, contact Ellyn at ellynhunter@charter.net

BBS Weight Loss Group: Saturdays, October 3, 10, 17, 24, and 31 at 12:00 noon Eastern Time

Facilitated by the members on a rotating basis, his is a weekly group for individuals who are using Weight Watchers, My Fitness Pal, or another weight-loss program to lose weight and would like to get together for more support, especially since so many of us in the BBS community are struggling with weight. The meetings are a great place to share ideas, recipes, and experiences, and to support each other throughout our weight management journey. The group meets using the Marshfield Clinic Zoom site.

BBS Adult Discussion Group: Sunday, October 11 at 7:00 pm Central Time.

This is a group for adults, both men and women, ages 30 and older. The purpose of the group is to provide adults with BBS with a collaborative forum to share their experiences, ideas and resources with one another, as well as to create interpersonal connections. The atmosphere is informal, and topics vary. The group meets by the Marshfield Clinic Zoom site monthly on a Sunday at 7:00 pm Central Time. For new members, before joining the group, contact Ellyn at ellynhunter@charter.net