

CRIBBS Newsletter

June 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.

We would like to share the following announcement from the BBS Foundation:

BBSF Family Conference: Washington, D.C.

More than 120 people from more than 50 BBS families and more than 25 scientists have already registered for this year's conference. Don't miss out on the chance to be a part of our largest conference yet! We will learn from BBS families from across the world as well as leading researchers and clinicians. Some potential agenda items and opportunities include:

- Learning from leading experts about cutting edge BBS research.
- Meeting representatives from Rhythm Pharmaceuticals to learn about IMCIVREE.
- Updating your CRIBBS information and participating in critical BBS research.
- Meet leaders of BBS Centers of Excellence from Marshfield, Mayo, Lurie Children's and PennMedicine.
- Connecting with BBS families and individuals in your region.
- Breakout sessions to learn about topics that are specific to your interests and concerns.

For more information or to register for the conference, please click [BBS Family Conference](https://bbsfamilyconference.org).

(<https://bardetbiedlsyndromefoundation.regfox.com/bbs-family-conference>)

For more information please reach out to Aline Charkoudian-Rogers at aline@bardetbiedl.org.

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



Marshfield Clinic[®]

Research Institute

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=vU39E3gPaR6U0OhwLi1LQ5XeRi8bSd.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 June 6 and Saturday July 4 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, June 26 at 7:00 pm Central Time

Please join us for the BBS parents support group. This group is facilitated by Maxie and David McGlohan and is geared toward parents of children with BBS from birth to age 18. But everyone is welcome to join in even if their loved one is older than 18. We will as always discuss any topics that parents wish to discuss. We welcome any newly diagnosed families to offer information and support. This group is a safe place where parents can discuss any and all issues. David Sr is a dentist and I'm a family nurse practitioner so we are very comfortable discussing dental and medical topics. We look forward to connecting with and supporting each other during these difficult times.

The group meets using the Marshfield Clinic Zoom site. For more information, contact Maxie at 2themax03@gmail.com

BBS Book Night: Friday, June 12, at 7:30 pm Central Time (moved to the second Friday this month only)

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 *Front Page Fatality*, by Lyndee Walker. Description: Crime reporter Nichelle Clarke's days can flip from macabre to comical with a beep of her police scanner. Then an ordinary accident story turns extraordinary when evidence goes missing, a prosecutor vanishes, and a sexy Mafia boss shows up with the headline tip of a lifetime. As Nichelle gets closer to the truth, her story gets more dangerous. Armed with a notebook, a hunch, and her favorite stilettos, Nichelle races to splash these shady dealings across the front page before this deadline becomes her last.

BBS Sports Club: Thursdays June 4, 11, 18, and 25, 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, June 28 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, June 6, 13, 20, and 27 at 12:00 noon Eastern Time

Facilitated by the members on a rotating basis, this 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, June 14 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