

CRIBBS Newsletter

June 2024



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.

This month we celebrate the 10-year anniversary of the first CRIBBS interview!

The BBS Foundation & Family Association has exciting news to share, the long-awaited international conference is on the calendar! Please join us in Minneapolis, Minnesota, July 26-28, 2024, as we connect with and learn from other BBS families, hear from leading experts about cutting edge research on BBS, and ask questions of doctors and specialists who have experience treating many people with BBS.

You can find more information about the conference including links to register at the BBS Foundation & Family Association website: <https://www.bardetbiedl.org/2024-conference-registration-form-1>

The CRIBBS registry continues to grow and we are fast approaching 800 participants. Your continued support of CRIBBS and willingness to take part in annual interviews is leading to important discoveries about BBS. We are so grateful for your time. Hearing from you every year is very helpful, even if it feels like not a lot has changed.

Please join if you have not joined CRIBBS by signing up on our webpage at www.bbs-registry.org. We wish to give thanks to the BBS Foundation that has provided HUGE support to CRIBBS.

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), the Zoom login for the BBS groups has changed. All the other BBS groups will meet on the new Marshfield Clinic BBS Zoom site as of the beginning of October:

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 Parents Support Group: Friday, June 28 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 7, at 7:30 pm Central Time

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 Lawnmower Blues, by Rex Anderson. Description: A reluctant PI who inherited the business from his granddad, Houston native Tony Aapt is under no illusion that being an investigator is glamorous: he mostly uncovers cheating spouses. Even so, Tony loves to regale bartender Maggie Hawk with scintillating stories about his profession: stories that happened to his grandfather, not to him. When Maggie wins the lottery, Tony is thrilled for her. He's even more thrilled when she gives him a fat retainer check to prove that her late husband, George, who died 33 years ago, didn't commit suicide.

BBS Sports Club: Thursdays June 6, 13, 20, and 27 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: Wednesday, June 19 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

normally meets every third Wednesday 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 1, 8, 15, 22, and 29 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 9 and 30 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 every third Sunday at 7:00 pm Central Time, except when holidays conflict. For new members, before joining the group, contact Ellyn at ellynhunter@charter.net