The Great Lakes Exstrophy Summer Campout



Friday, July 23 to Sunday, July 25, 2027

Join us for a fun weekend to get to know other families living with exstrophy!



You are invited to join us for a weekend campout for anyone with bladder exstrophy, cloacal exstrophy, cloaca, epispadias and hypospadias, and their families and friends. This is a great way to connect with other families, share in similar experiences and know that you are not alone! To view some videos about what our campouts are like, go to Tom Exler's "Courage to Shine" website here: https://courage-to-shine.org/2016/07/04/the-a-be-c-great-lakes-chapter-annual-summer-campout/

Location and Facilities

Eby's Pines RV Park & Campground (http://www.ebyspines.com) in Bristol, Indiana is located in the scenic forests of northern Indiana's Amish Country. It is just minutes from the Indiana Toll Road.

Eby's Pines has tent sites, full hook-up sites, pull-thru sites, and cabins, as well as two heated pools and a playground. For address and contact info, see p. 3 of this flyer.





Activities

Join us on Friday and Saturday evenings in the *Shady Lane* area of the campground as we gather around the campfire and enjoy s'mores. We have reserved the *Island Pavilion* for Saturday, where everyone is invited join us for a picnic lunch at 11:30am—we will provide hot dogs, chips, cookies, and bottled water—followed by a group photo at 12:45pm. The rest of the time will be unscheduled for swimming, games, crafts, and—most importantly—having fun with old friends and making new ones!

Cost of Participation

There is ***no registration cost*** for the campout! You will need to pay for your campsite (at Eby's Pines) or local hotel accommodations. If staying at a hotel, day passes are required to park at Eby's Pines—for more details, see Question #4 on the page of "FAQ" (p. 2).

Whether you are camping at Eby's Pines, staying at a nearby hotel, or visiting just for the picnic on Saturday, July 24, please contact Alice Ambrose to let her know the number of people coming with you. You may call or text her at (616) 406-7857, or e-mail her at bradnalice@yahoo.com.

Reservations

You may at any time reserve a campsite for the 2027 campout by following this link or scan the QR code at right to the Eby's Pines online reservation form. (For a campground map and other details about Eby's Pines, visit their website: https://ebyspines.com/.) You may also call Eby's Pines directly at **(574) 848-4583.** Please reserve as soon as possible, especially if you prefer a specific accommodation (such as a camping cabin).

If you are interested in coming but don't want to camp, there are several nice hotels within a short drive from Eby's Pines. The nearest hotel is Hampton Inn & Suites in Middlebury, IN (phone (574) 822-0288). Additional hotel information for Shipshewana, IN, can be found at: http://www.Shipshewana.com

Frequently Asked Questions about the Great Lakes Exstrophy Campout

Q1: **Who can attend the campout?**

A: *Anyone* of *any* age, adults and children, living with bladder exstrophy, cloacal exstrophy, cloaca, epispadias and hypospadias are invited to attend, along with their immediate families, extended families, and friends! Also, you don't need to live in a "Great Lakes" state. (Campers have come from as nearby as Middlebury, IN, and as far away as Washington, Massachusetts, and Ontario, Canada!) Since our first campout in 2009 we have seen more and more families attend—ranging from 20 to 30 families—and the ages of those with exstrophy have ranged from toddler age to adults in our 50's!

Q2: **What is the typical schedule of events for the weekend of the campout?**

A: On the evenings of Friday (July 23) and Saturday (July 24) we are planning a campfire at one of our group's campsites along Shady Lane. On Saturday everyone is invited to the Island Pavilion for games, crafts, and conversation. Starting at 11:30 am on Saturday, join us at the Island Pavilion for a picnic lunch followed by a group photo at 12:45 pm. Apart from these activities, the rest of the time is unscheduled so that everyone can enjoy the campground facilities and nearby attractions as they so choose. (*Note:* You are welcome to arrive a day or two early and/or stay an extra day or two after the weekend, as some families have done in the past. That way, the campout can be part of a longer vacation and you can visit even more with other families who do the same!)

Q3: **What can we bring to the picnic lunch on Saturday?**

A: Whatever you would like!... If you do bring a dish to share, please *bring a list of ingredients* to place next to your dish out of concern for those who have food allergies. Please don't feel obliged to bring anything, though! We will provide hot dogs (including skinless hot dogs and gluten-free buns), chips, cookies, and bottled water, as well as plates, plastic ware, and napkins.

Q4: **We are inexperienced and/or unexcited when it comes to camping, whether in tents or RVs. Must our family "camp out" to come to the campout?**

A: You do *not* need to camp to attend the campout! Several nice hotels are located a short drive from Eby's Pines. Our recommendation is Hampton Inn & Suites in Middlebury, IN (see preceding page for details). Unfortunately we cannot offer any camping equipment to borrow.

If you plan to stay in a local hotel, please be aware that visitors to Eby's Pines must check in at the campground office upon arrival and obtain a day pass in order to use the pool, playground, and other campground facilities. (Please call Eby's Pines directly at **574-848-4583** for the cost of a 2027 day pass.) However, if you are visiting Eby's Pines for just Saturday, July 24, then tell the staff person at check-in that you are joining the "Ambrose group" at the Island Pavilion. Your Saturday day pass should then be free of charge.

Q5: **Are there scholarships or other financial help available to cover travel costs for the campout?**

A: Unfortunately not at this time. The cost of the Saturday picnic lunch and renting the Island Pavilion for that day has been paid for out-of-pocket by the campout coordinators. In the past we (Alice and her husband Brad) received private donations that helped offset some of these costs. We do not receive financial support from A-BE-C.

Q6: **I wish there were a campout closer to me!**

A: There can be! All that is needed is one person or family to serve as a point of contact, select a date and site, and get the word out. Exstrophy-related Facebook groups—including the private group for this campout, named "GLC 2027 :)"—are great for free publicity!) Alice has experience coordinating regional campouts both here and in Washington state, so please feel free to contact her if you would like more details or suggestions on getting started!

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(continued)

Additional resources

There is a **private Facebook group** called **"GLC 2027 :)"**, for this campout! Other private Facebook groups exist for exstrophy patients and families too; please contact **Alice Ambrose** (email her at bradnalice@yahoo.com) for help to get connected.

The **Youth Rally** is an annual camp experience for youth living with conditions of the bowel and/or bladder system. Their mission is to provide an environment for youth and adolescents that encourages self-confidence and independent living: https://youthrally.org/

Also, check out their "FAQ" page for a link to the Facebook group page for the Youth Rally as well as links to numerous other websites for great information: https://youthrally.org/faq

The **A-BE-C** is an international support network for parents and families with bladder exstrophy (including classic exstrophy, cloacal exstrophy, and epispadias), and health care providers who work with patients and families living with bladder exstrophy: http://www.bladderexstrophy.com

Contact Information for Eby's Pines RV Park & Campground

Eby's Pines is located in the scenic forests of Northern Indiana Amish Country. The campground is just minutes from the Indiana Toll Road (I-80/90) on State Road 120.

Eby's Pines Campground
14583 State Road 120
Bristol, IN 46507

Phone: (574) 848-4583 *(ask for Teresa!)*
Web: www.ebyspines.com

WE HOPE TO SEE YOU AT OUR SUMMER 2027 GREAT LAKES EXSTROPHY CAMPOUT!!!