# The A-BE-C Great Lakes Chapter 11<sup>th</sup> Annual Summer Campout

Friday, July 26 to Sunday, July 28, 2019



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 dealing 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 photos and videos about what our campouts are like, go to the "Courage to Shine" website, courage-to-shine.org, and search for "Great Lakes Chapter" (Thanks to Tom Exler, webmaster for "Courage to Shine"!)

Whether you are camping at Eby's Pines, staying at a nearby hotel, or visiting just for the day, please contact **Alice Ambrose** to let her know you are coming! You may call or text her on her cell phone at (616) 406-7857, or e-mail her at bradnalice@charter.net.

#### **Location and Facilities**

Eby's Pines RV Park & Campground (<a href="http://www.ebyspines.com">http://www.ebyspines.com</a>) 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 driving directions, see the last page of this flyer.





#### Activities

We have reserved a block of sites in the *Shady Lane* area of the campground, where we will enjoy a campfire and s'mores on Friday and Saturday evenings. Starting at 11:30am on Saturday join us for a picnic lunch—we will provide hot dogs, chips, and bottled water—at the *Island Pavilion*, a short walk from the swimming pools. The rest of the time will be unscheduled for swimming, games, exploring the Shipshewana area, and—most importantly—having fun with old friends and making new ones!

### Reservations

Eby's Pines is now accepting reservations for campsites for our 2019 campout. Please call Eby's Pines as soon as possible to ensure availability and so that our campsites can be together in the Shady Lane area. To make your reservation, please call the campground directly at (574) 848-4583 and give the staff your name and contact information. (Do NOT use the campground's online reservation system; please call the campground directly.) Reservations may be paid for by credit card over the phone.

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 A-BE-C Great Lakes Campout

# Q: Who can attend the campout?

A: Anyone of <u>any</u> 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 Massachusetts and Ontario, Canada!) For our past few years we have had an increasing number of families attend—ranging from 20 to 25 families—and the ages of those with exstrophy have ranged from toddler age to adults in our 40's!

### Q: What is the typical schedule of events for the weekend of the campout?

A: On the evenings of Friday (July 26) and Saturday (July 27) we are planning a campfire at one of our group's campsites along Shady Lane. On Saturday, from 9:00 am to 5:00 pm, everyone is invited to the Island Pavilion for games, crafts, and conversation. Starting at 11:30 am on Saturday, join us for a picnic lunch served at the Island Pavilion. 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!)

# Q: What can we bring to the picnic lunch on Saturday?

A: Whatever you would like—but please don't feel obliged to bring anything! We will provide hot dogs (including skinless hot dogs, gluten-free buns, and vegan options too), chips, and bottled water, as well as plates, plastic ware, and napkins.

# Q: 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: Not a problem! We cannot offer any camping equipment to borrow, but several nice hotels are located a short drive from Eby's Pines. (Our favorite, closest hotel is Hampton Inn & Suites in Middlebury, IN; see preceding page for details.)

If you plan to stay in a local hotel, please be aware that visitors to Eby's Pines must register 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 2019 day pass fees.) However, if you plan to visit Eby's Pines for just Saturday, July 27 then, upon registering at the campground office, tell the staff person you are joining the "Ambrose group" at the Island Pavilion; your day pass should then be free of charge. (Because we have already reserved the Island Pavilion for July 27, you should not need to have to pay for a day pass that day.)

## Q: 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. Over the past few years we (Alice and her husband Brad) had received donations (for example, from doctors with whom Alice used to work) that helped offset some of these costs. However, we do not receive financial support from A-BE-C, despite being affiliated with them.

#### Q: 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 have been 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 to more details or suggestions on getting started!

# The A-BE-C Great Lakes Chapter 11<sup>th</sup> Annual Summer Campout

Friday, July 26 to Sunday, July 28, 2019 *(continued)* 

The A-BE-C is an international support network of individuals with bladder exstrophy (including classic exstrophy, cloacal exstrophy, and epispadias), local parent-exstrophy support groups, and health care providers who work with patients and families living with bladder exstrophy. <a href="http://www.bladderexstrophy.com">http://www.bladderexstrophy.com</a>



The Great Lakes Chapter of The A-BE-C is a regional network serving the Great Lakes states (MI, MN, WI, IL, IN, NY, PA, and OH) as well as Ontario.

**Did you know...** that there are **support groups on Facebook** for exstrophy patients and their families? Please contact **Alice Ambrose** (email her at <a href="mailto:bradnalice@charter.net">bradnalice@charter.net</a>) to get connected. There are specific private groups as well as a general group for exstrophy patients and families.

#### Directions to 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 Web: www.ebyspines.com

**Directions from Ohio and points east:**Following I-80/I-90 West toll road, take **Exit 107 Middlebury Exit.** Go South on SR 13 for 1 mile to SR 120. Turn West onto SR 120 and go 3 miles. Eby's Pines is on the South side of the road.

**Directions from Chicago and points west:** Following I-80/I-90 East toll road, take **Exit 101 (Bristol Exit).** Go South on SR 15 for 2 miles to SR 120. Turn East onto SR 120 and go 3 miles. Eby's Pines is on the South side of the road.



WE HOPE TO SEE YOU AT OUR SUMMER 2019 GREAT LAKES EXSTROPHY CAMPOUT!!!