

# Establishing a Comprehensive Online Patient Recommendation-Based Pediatric Spina Bifida Resource Repository

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**Boston Children's Hospital**  
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# Background and Aim

- Pediatric spina bifida (SB) patients lack access to many activities available to healthy children and adolescents
- Caregivers may feel unsupported in seeking out special activities or services
- Limitations in existing online resources
- Aim: Development of an updated, accessible, comprehensive pediatric SB patient resource repository via direct patient interviews



# Methods

- Prospective interviews of clinic SB patients
- Encouraged to share resources and unmet needs at the conclusion of each interview
- Assembled online database with a brief description, link, contact information, and dates where appropriate



# Results

- 15 patients and families recommended more than 50 resources
- Most (74%) recommendations collected fall under the categories of *summer camps*, *adaptive activities*, and *clothing and shoe brands*
- The most prevalent unmet need, shared by 4/15 patients, is *affordable and accessible transportation options*
- The project has been met with universal enthusiasm by caregivers



Summer Camps



Adaptive Sports and Activities



Clothing



Miscellaneous



Transportation



# Representative Image of Summer Camp List in Online Resource Repository

Summer Camp	Description	Location	Dates	Ages	Website	Contact
The Youth Rally	(Overnight Camp) Each year, the Youth Rally hosts kids and teens living with conditions of the bowel and bladder at a college campus for a 5-night one of a kind camp experience that promotes independence, self-esteem, learning, friendship, and FUN!	Seattle, WA	July 8th - 13th, 2019	11 - 17	<a href="http://www.youthrally.org/">http://www.youthrally.org/</a>	April Gimlen – Director, Program & Outreach. Youth Rally Parent. April@youthrally.org
Camp Spifida	(Overnight Camp) At Camp Spifida we believe that every child should be able to spend a week at camp - laughing, swimming, and singing around the campfire, but, for children with spina bifida, summer camp was only a faraway dream until Camp Spifida was formed 11 years ago. Camp Spifida offers a full week of lots of exciting activities, such as; craft projects, fishing, swimming, dancing, paddle boats, pontoon boat rides, campfires, hayrides, woodworking, ropes challenge course and the exciting 26 foot high climbing wall. Most importantly camp offers children with spina bifida a chance just to be kids!	Port Trevorton, PA	Begins July 21, 2019	6 - 18	<a href="http://campspifida.org/">http://campspifida.org/</a>	Request info here: <a href="http://campspifida.org/request/">http://campspifida.org/request/</a> Email: spifida@ptd.net
Double H Ranch	(Overnight Camp) Since the Double H Ranch officially opened its doors on July 4, 1993, it has served over 60,000 children dealing with life-threatening illnesses from around the world. It was the second "Hole in the Wall Camp" in what has become a worldwide network of not-for-profit recreational and therapeutic experiences for children with serious illness. The mission of the Double H Ranch is to provide specialized programs and year-round support for children and their families dealing with life-threatening illnesses. Our purpose is to enrich their lives and provide camp experiences that are memorable, exciting, fun, empowering, physically safe and medically sound. All programs are FREE of charge and capture the magic of the Adirondacks.	Lake Luzerne, New York	June 22 - August 21, 2019	6 - 21	<a href="https://www.doublehbranch.org/contact/">https://www.doublehbranch.org/contact/</a>	Main Office – 518-696-5676; <a href="https://www.doublehbranch.org/contact/">https://www.doublehbranch.org/contact/</a>
Therapeutic Summer Camp through the Center for Human Development (CHD)	(Day Camp) In partnership with Western New England University, CHD's Disability Resources is offering a therapeutic summer camp for kids! Children Ages 6-14 of all abilities participate in this one-of-a-kind camp! Enjoy a supportive environment designed to help children increase their feelings of self-esteem and improve their social, physical and psychological competence! Various activities will be offered. Some of last years offerings included talent shows, outdoor water fun and games and chalk drawing!	Western New England University, Springfield, MA	June 24 - 28, 2019	6 - 14	<a href="https://chd.org/adult-services/">https://chd.org/adult-services/</a>	Please register by June 10, 2019 at CHD.org/DR. Program Manager Jessica Levine (413) 788-9695
Camp Jabberwocky	(Overnight Camp) Camp Jabberwocky offers children and adults with a wide range of disabilities the chance to enjoy the summer in a small family-like community – living together and enjoying jam-packed days filled with adventurous activities and experiences that are safe, empowering, exciting and fun. Campers stay between one and four weeks during which they enjoy activities and classes on campus and out and about in the community of Martha's Vineyard. At Jabberwocky, people with different abilities form the majority in the community. Their needs become priority needs; their concerns become concerns. And in this age, when cultural and individual sense of belonging is waning, a community that works is a light of hope.	Martha's Vineyard, MA	June 22 - August 19, 2019	All ages, including adults	<a href="https://www.campjabberwocky.org/">https://www.campjabberwocky.org/</a>	Phone: 508-560-8450; Email: info@campjabberwocky.org



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# Conclusions

- We provide a framework for the establishment of a patient/family recommendation-based resource repository for pediatric SB patients
- Hope to collaborate with other institutions to approach their patients who can contribute to this novel resource
- Necessary to obtain direct patient feedback on the value and utility of the resource repository
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