

## Childhood Cancer Survivorship Resources

**\*This list is subject to change and is not an exhaustive list. Providing references to other organizations or links to other websites does not imply that OHSU endorses the information or services provided by them. Those organizations and/or websites are responsible solely for the information they provide.**

**Listing of resources and websites is for informational purposes only.**

### General Survivorship Resources:

Doernbecher Survivorship Clinic Facebook page: search Doernbecher-Cancer-Survivors-Clinic and click “follow” for information about local events, resources, and general survivorship information

Doernbecher Cancer Survivorship Website <https://www.ohsu.edu/doernbecher/doernbecher-cancer-survivorship-program>

Pediatric Brain Tumor Foundation Survivorship Guidebook  
[https://curethekids.formstack.com/forms/survivorship\\_resource\\_guidebook](https://curethekids.formstack.com/forms/survivorship_resource_guidebook)

BMT Info Net: Various resources for survivors and caregivers <https://www.bmtinfonet.org/>

Book: Childhood Cancer Survivors: A practical guide to your future (Keene, Hobbie, Ruccione)

<https://www.childhoodcancerguides.org/our-books/childhood-cancer-survivors/>

### Teen and Young Adult Resources & Supports:

*Stupid Cancer* is a non-profit organization that provides young adult cancer support  
<http://www.stupidcancer.org/>

*Lacuna Loft* provides online wellness support programs and resources, lifestyle encouragement, and peer support community for young adults with a cancer experience <https://lacunaloft.org/>

CancerCon annual conference for young adult cancer survivors  
<https://stupidcancer.org/events/cancercon/>

Children’s Hospital of Philadelphia Survivorship Manual for teens and young adult survivors  
<https://media.chop.edu/data/files/pdfs/oncology-aya-survivorship-manual.pdf>

Project Koru offers camps, retreats, and workshops to help cancer survivors diagnosed between 18-39  
<https://www.projectkoru.org/why-we-exist/>

Epic Experience offers free week-long outdoor camp experiences for individuals (ages 18+) who have been diagnosed with cancer at any time in their lives <https://www.epicexperience.org/>

First Descents is a multi-day adventure program for young adult cancer survivors  
<https://firstdescents.org/>

True North Treks offers outdoor adventures for teen and young adult cancer survivors and caregivers  
<http://www.truenorthtreks.org/>

## **Educational Resources:**

Learning & Living with Cancer Booklet: Advocating for your child's educational needs

[https://www.livestrong.org/sites/default/files/Learning\\_Living\\_with\\_Cancer.pdf](https://www.livestrong.org/sites/default/files/Learning_Living_with_Cancer.pdf)

<http://www.survivorshipguidelines.org/pdf/EducationallIssues.pdf>

*Educational Issues Following Treatment for Childhood Cancer with associated supports/resources:*

<http://www.survivorshipguidelines.org/pdf/EducationallIssues.pdf>

*SamFund Webinar* about college financial assistance for childhood cancer survivors

<https://www.youtube.com/watch?v=lnKvYZl1Cho>

*The National Grace Foundation* offers college admissions and financial aid counseling and advocacy to young cancer survivors and their families <http://graceamerica.org/GraceFoundation/services/>

Financial aid information and scholarships for individuals experiencing disability

<https://www.onlineschools.org/financial-aid/disabilities/>

Scholarships for college textbooks for childhood cancer survivors: Scholarships of up to \$1,000 per year, renewable for up to five years, are offered to cover textbook expenses for individuals being treated for or who are survivors of childhood cancer [www.survivorvision.org](http://www.survivorvision.org)

## **Financial & Career Assistance**

*Triage Cancer* provides education on the practical and legal issues that may impact individuals diagnosed with cancer and their caregivers, through free events, materials, and resources <https://triagecancer.org/>

*Cents Program* to help people affected by cancer to protect their financial situations

[www.centsprogram.org](http://www.centsprogram.org)

*Samfund Living Grant* for young adults after cancer <http://www.thesamfund.org/get-help/grants/>

*Leukemia and Lymphoma Society* healthcare related costs that includes long-term follow up care and insurance premium help: <http://www.lls.org/support/financial-support>

*Cancer and Careers* empowers and educates people with cancer and survivors to thrive in their workplace, by providing expert advice, interactive tools and educational events:

<https://www.cancerandcareers.org/en>

*Samfund & Triage Cancer Finances Toolkit* for young adults with a cancer experience. Gives in-depth information about disability benefits, health insurance, employment, medical bills, and managing money: <https://cancerfinances.org/toolkit/>

*Vocational Rehabilitation* is available to individuals experiencing barriers to employment and provides training and support to find a sustainable career in every county across the nation. Services are free of charge: <https://www.oregon.gov/dhs/employment/VR/Pages/index.aspx>

US Gov Office of Equal Opportunity website with info regarding requesting reasonable workplace accommodations due to a medical condition:

[https://www.eeoc.gov/eeoc/internal/reasonable\\_accommodation.cfm](https://www.eeoc.gov/eeoc/internal/reasonable_accommodation.cfm)

## **Individuals and families experiencing disability:**

How to apply for SSI <https://www.ssa.gov/ssi/text-apply-ussi.htm>

Info about disability benefits and the disability process <https://www.ssa.gov/benefits/disability/>

*Oregon and Washington's Guide to Accessible, Inclusive, and Adaptive Activities: Fun for Everyone:* <https://madmagz.com/magazine/1081928#/>

*The ARC:* Comprehensive list of community resources for individuals and families experiencing developmental disabilities <https://thearcoregon.org/resources/community-resources/>

*Adaptive Sports NW*-for children and adults experiencing disability: <http://www.adaptivesportsnw.org>

*Oregon Adaptive Sports (OAS)* in Deschutes county/Bend area offers adaptive sports lessons/outings youth and adults experiencing. Scholarships are available. <https://oregonadaptivesports.org/sports/register/>

*Oregon Family to Family Health Center* supports families and caregivers of children with special health needs to navigate the complex health care systems. This website houses hundreds of resources for parents, grandparents, teens, and young adults: <https://www.ohsu.edu/oregon-family-to-family-health-information-center>

*The ARC:* Information about legal guardianship and less restrictive alternatives such as supported decision making <https://thearcoregon.org/gaps/guardianship/>

## **Outdoor Camps for Children & Families:**

**Ukandu:** The mission of UKANDU is to bring joy, hope, and connection to communities impacted by childhood and adolescent cancer through free virtual and in person camp-like experiences. <https://campukandu.org/come-to-camp/>

*Camp Agape:* a family residential camp in Oregon that offers a summer camp experience to cancer-afflicted children and their families <https://campagapepdx.com/>

*Camp Millennium:* a free summer camp for children with a cancer experience and their siblings outside of Roseburg, Oregon. <https://campmillennium.org/>

*Candlelighters Family Camp:* a free three day summer camp for families affected by childhood cancer who are currently undergoing treatment, in remission, or bereaved <https://www.candlelightersoregon.org/index.php/programs/family-camp>

*Camp Korey* in Washington empowers children living with serious medical conditions and their families through year-round, life-changing experiences, always free of charge <https://www.campkorey.org/>

*Roundup River Ranch* in Colorado offers old-fashioned, pure fun camp experiences for children with serious illnesses and their families. Children must be within three years of active treatment and/or currently experiencing the challenges of a chronic or serious condition <https://roundupriverranch.org/>

## **Support Groups & Peer Support:**

*CoHeals*: a free app for connecting and building relationships among families impacted by pediatric cancer <https://coheals.com/>

*Young Adult Writing Group at OHSU*. This weekly group is for people ages 15 to 39. This is not a workshop where you will learn to write, and you do not need writing experience to participate. Email facilitator Dawn Thompson to register: [dawnrenethompson@gmail.com](mailto:dawnrenethompson@gmail.com)  
<https://www.ohsu.edu/knight-cancer-institute/support-groups-and-classes-cancer>

*The Luminaries*: a Candlelighters program for teens ages 13-19 who have experienced cancer (and their siblings) to connect and support one another through social connections and service projects. For more information email [Lisa@candlelightersoregon.org](mailto:Lisa@candlelightersoregon.org)  
<https://www.candlelightersoregon.org/index.php/family-activity/teen-programs>

*OHSU Mindfulness Based Stress Reduction (MBSR)* 8-week course and drop in groups for cancer patients, survivors, and caregivers. Research shows that cancer patients who complete the course report reductions in pain, fatigue, anxiety and sleep disturbance and an overall increase in quality of life. Classes include meditation instruction and practice, group discussions and educational presentations on the relationships between mindfulness, stress, and wellness.  
<https://www.ohsu.edu/xd/health/services/mindfulness/>

*Children's Cancer Association*: Joy-centric programs (music, mentorship and nature) to create feel-good moments for patients. <https://joyrx.org/>

## **Mental Health & Emotions**

Emotions after childhood cancer

[http://www.survivorshipguidelines.org/pdf/healthlinks/English/emotional\\_issues\\_Eng.pdf](http://www.survivorshipguidelines.org/pdf/healthlinks/English/emotional_issues_Eng.pdf)

Information for survivors on emotions (National Children's Cancer Society)

<https://www.thenccs.org/emotions/>

*Psychology Today Therapist Search Engine* is a tool that can be used search for a therapist by insurance type, group or individual therapy, issue, geographical area, etc.  
<https://www.psychologytoday.com/us/therapists>

24/7 National Suicide Prevention Lifeline Hotline and online chat feature 1-800-273-TALK (8255)  
[Lifeline \(suicidepreventionlifeline.org\)](http://Lifeline(suicidepreventionlifeline.org))

Lines for Life Youthline - Call 877-968-8491 or text teen2teen to 839863 <https://oregonyouthline.org/>

## **General Health and Wellness**

Free summer fitness pass for teens ages 15-18 <https://www.planetfitness.com/TeenSummerChallenge>

Parks and Recreation facilities in counties across the state often offer financial aid for classes, gym memberships, and pool passes <https://www.portland.gov/parks/recreation>

*Survivorship Guidelines* patient education links (diet and exercise, skin health, dental health and more)  
<http://survivorshipguidelines.org/>

## **Transition to Adulthood in Healthcare**

Family Readiness Toolkit: <https://www.gottransition.org/resource/?hct-family-toolkit>

A healthcare transition quiz for teens: <https://www.gottransition.org/youth-and-young-adults/hct-quiz.cfm>

A sample transition readiness checklist for teens <https://www.gottransition.org/6ce/?leaving-readiness-assessment-youth>