

# **BRAVING NEUROBLASTOMA**

## *resource guide*

Within this brochure, you will find educational resources to support you in understanding neuroblastoma, exploring research and treatment options, and emphasizing the significance of mental health and community connection.

STORIES OF HOPE

LIFE AFTER TREATMENT

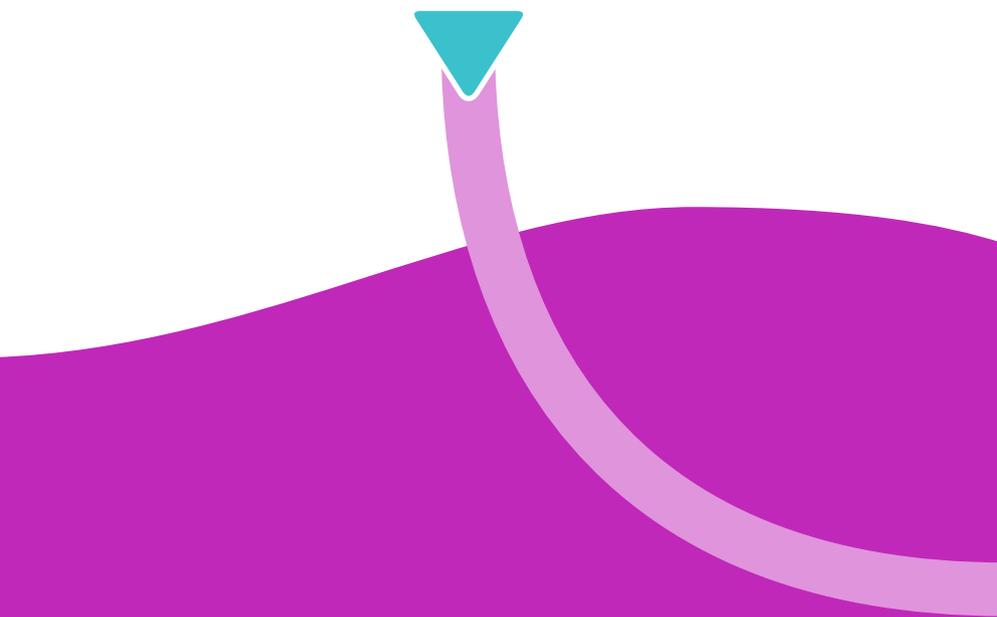
FINDING COMMUNITY AND SUPPORT

COPING AND MENTAL HEALTH

STAYING ORGANIZED

TALKING TO YOUR CHILD

RESEARCH AND TREATMENT INFORMATION



# Welcome to the Braving Neuroblastoma Resource Guide

Navigating the complexities of neuroblastoma can be overwhelming, but you are not alone. The resources in this brochure are part of the Braving Neuroblastoma suite of materials. This is your comprehensive guide, offering support and valuable information at every step of the neuroblastoma journey.

Look for these tags to know when a resource might be most helpful:

-  **NEWLY DIAGNOSED**
-  **IN TREATMENT**
-  **AFTER TREATMENT**
-  **THROUGHOUT THE JOURNEY**

As you explore this brochure, we encourage you to visit **BravingNeuroblastoma.com**, where you can find most of the resources that are listed here, plus valuable information on neuroblastoma and what to expect from this journey. Scan the QR code below to visit.

 When you spot the laptop icon, know that the resource is available on our website.



Your journey is important to us, and we are here to provide not only information but also a sense of community. We invite you to connect with us beyond these pages by following us on social media.

   **@BravingNeuroblastoma**

Additionally, visit the Neuroblastoma Parent Global Symposium YouTube channel to stay informed on the latest developments and to watch videos from past symposiums.

 **@neuroblastomaparentglobals1684**

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## Research and treatment information

In this section, hear from a pediatric oncologist, a nurse practitioner, and a social worker as they discuss a variety of neuroblastoma topics that may arise during different points in the journey.

Find all these videos on our YouTube  
@BravingNeuroblastoma



### Neuroblastoma Research Groups

Find on

Discover different research groups and the goals of their research.



### Treatment and Clinical Trials

Find on

Learn why clinical trials are important and may be an option for your child.



### Understanding Clinical Trials

Find on

Gain insight into understanding clinical trials.



### Relapsed/Refractory Neuroblastoma

Find on

Watch a discussion on treatment and hope during this phase of your child's journey.



### From our friends at Solving Kids' Cancer—Parent Global Symposium:

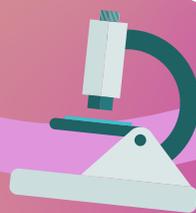


### Neuroblastoma Basics: Introduction to Neuroblastoma

Find on @neuroblastomarentglobals1684

Explore neuroblastoma basics, including treatment options, imaging, and side effects.

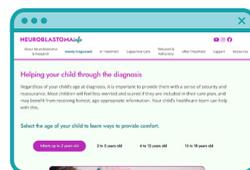
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## Talking to your child

The resources in this section can help you explain neuroblastoma and treatment in a way that is easier for your child to understand.



### Helping Your Child Through the Diagnosis

Find on 

Discover age-appropriate tips to help your child cope with a neuroblastoma diagnosis.



### The Big Adventures of Little Skivolo

Find on 

In this book, meet Skivolo, a red panda with high-risk neuroblastoma. He provides easy-to-follow information about neuroblastoma and what your child can expect.

*Available in English, Spanish, and French.*



### The Next Big Adventure of Little Skivolo

Find on 

This book follows Skivolo as he starts antibody therapy, helping to explain how this medicine works in a way that's easy for your child to understand.

*Available in English, Spanish, and French.*



### Braving Neuroblastoma Toolkit

Find on 

The toolkit includes all the Skivolo books and a treatment calendar for remembering important dates. It also has medical play tools to help children understand their diagnosis and treatment while giving them a way to talk about their thoughts and feelings.



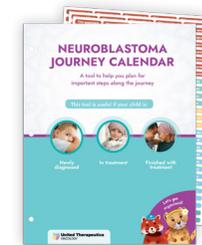


Find these items and more in the resource section of the website.



## Staying organized

Use these resources to help keep your child's care on track.

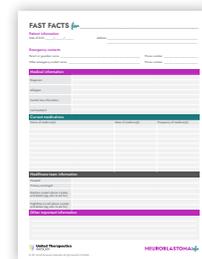


### Treatment Journey Calendar

Find on  as part of the Braving Neuroblastoma Toolkit

Keep track of important dates and key milestones in your child's treatment journey.

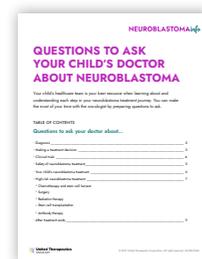
Available in English and Spanish.



### Fast Facts for Your Child

Find on 

Be sure those caring for your child have all of the important medical information they need in case of an emergency.



### Questions to Ask Your Doctor

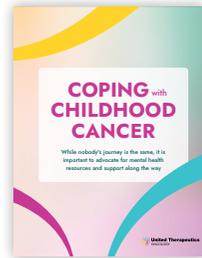
Find on 

Prepare for conversations with your healthcare team and ask important questions about your child's care at each step of the journey.



## Coping *and* mental health

The resources in this section can be used throughout the neuroblastoma journey to help prioritize both you and your child's mental health.



### Coping With Childhood Cancer Guide

Find on 

A step-by-step guide to help set a good foundation for you and your child's mental health throughout the journey.



### Coping With Childhood Cancer Kit

Find on 

This kit provides information for you and your family on how to manage stress and anxiety during the treatment journey. Learn more about what's in the kit on our website.



### Coping With a Neuroblastoma Diagnosis

Find on  

Learn how to help your child and family cope with the diagnosis.



### Mental Health and the Childhood Cancer Journey—A Panel Discussion

Find on  

Watch as 5 panelists, including families, survivors, and a psychosocial expert, talk about mental health in relation to the childhood cancer journey.



### The Impact on Siblings

Find on  

Discover the impact that childhood cancer can have on siblings and what steps can be taken to ensure the needs of siblings are met.



## From our friends at Solving Kids' Cancer—Parent Global Symposium:



### Dealing With a Childhood Cancer Diagnosis

Find on  [@neuroblastomarentglobals1684](https://www.youtube.com/@neuroblastomarentglobals1684)

Learn practical tips for processing and responding to a childhood cancer diagnosis.

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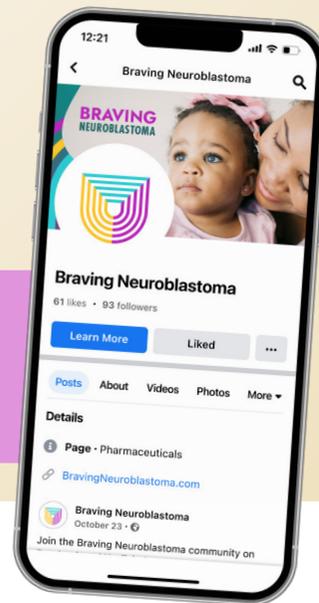


## Finding community and support

### Follow Braving Neuroblastoma on social media

   @BravingNeuroblastoma

Braving Neuroblastoma is an online community fostering education and connection with other families who are battling neuroblastoma, allowing them to help one another navigate the complex challenges that arise on this journey.



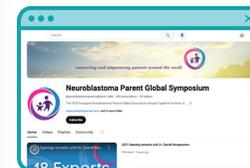
### Neuroblastoma Support and Advocacy Groups

Find on 

These groups provide helpful information and support for families, like yours, who are coping with a childhood cancer diagnosis.



### From our friends at Solving Kids' Cancer and Coalition Against Childhood Cancer:



### Neuroblastoma Parent Global Symposium YouTube channel

Find on  @neuroblastomarentglobals1684

This channel provides support and information for families affected by neuroblastoma, bringing them together with researchers and medical professionals who work to treat and support them. Watch videos from past symposiums on a variety of topics from clinical trials to challenges of childhood cancer.



### Hope Portal

Find on 

The Hope Portal is a comprehensive directory of organizations nationwide that aims to connect childhood cancer families to valuable support and resources.



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## Life after treatment

The resources in this section can help guide the transition after treatment ends.



### Zara Takes Off

Find on

This book features Skivolo's friend Zara, who has finished her neuroblastoma treatment, as she learns about what to expect after treatment and the kind of follow-up care she'll receive.

Available in English, Spanish, and French.



### Importance of After Treatment Follow-Ups

Find on

Learn why long-term follow-up care is important for your child after they complete their treatment.



### Late and Long-Term Side Effects

Find on

Learn about potential late and long-term side effects of neuroblastoma treatment.



## From our friends at Coalition Against Childhood Cancer:



### CAC2 Survivorship Toolkit

Find on [CAC2.org](https://www.cac2.org)

This toolkit provides a library of resources compiled by experts and advocates to help ensure childhood cancer survivors and their families have access to up-to-date information.

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## Stories of hope

Explore these resources where individuals and families share their inspiring journey of resilience in the face of neuroblastoma.



### Still Standing Together

Find on  

Leah Still was diagnosed with neuroblastoma at just 4 years old while her father, Devon, was making a name for himself in the NFL, and together they want to share their story in the hopes of helping others find strength and support in their own journeys. Watch as Devon and Leah share their journey with neuroblastoma.



### How Regoaling Can Reboot Your Life

Find on  

Learn about the important skill of regoaling and how it can help you and your child navigate the childhood cancer journey.



### From our friends at Solving Kids' Cancer—Parent Global Symposium:



### Neuroblastoma Has Shaped But Not Defined Me

Find on  [@neuroblastomarentglobals1684](https://www.youtube.com/@neuroblastomarentglobals1684)

Hear from 2 neuroblastoma survivors on how childhood cancer has not defined them.

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United Therapeutics Oncology is dedicated to the care of children with neuroblastoma. We are honored to serve this brave community and are committed to providing comprehensive care to the families and caregivers touched by this childhood cancer.