



2026 ACTION DAYS INFORMATION

Issues and Advocacy Training

February 24-25, 2026

Washington, D.C.

*Alliance for
Childhood
Cancer*





Each year, the Alliance for Childhood Cancer hosts a two-day event that combines advocacy training with meetings on Capitol Hill giving participants the opportunity to engage directly with Members of Congress and their staff.

The Alliance's goal is to provide the childhood cancer community - survivors, parents, children, healthcare professionals, and others with the opportunity to visit with their members of Congress and staff on Capitol Hill to advocate for important childhood cancer issues currently before Congress.

Founded in 2001, the Alliance for Childhood Cancer is a forum of national patient advocacy groups, and medical and scientific organizations. These organizations meet regularly in Washington, D.C. to share ideas and concerns and work collaboratively to advance policies leading to improved research, public education, and diagnosis, treatment, supportive care and survivorship for children and adolescents with cancer.

Alliance Full Member Organizations

American Academy of Pediatrics
American Association for Cancer Research
American Cancer Society Cancer Action Network
American Childhood Cancer Organization
American Society of Pediatric Hematology/Oncology
Andrew McDonough B Positive Foundation
Association for Clinical Oncology
Association of Pediatric Hematology-Oncology Nurses
Association of Pediatric Oncology Social Workers
Blood Cancer United (*Formerly Leukemia & Lymphoma Society*)
Children's Brain Tumor Foundation
Children's Cancer Cause
Children's Oncology Group Foundation
Mattie Miracle Cancer Foundation
MIB Agents
National Brain Tumor Society
Pediatric Brain Tumor Foundation
Rally Foundation for Childhood Cancer Research
St. Baldrick's Foundation

Associate Member Organizations

Dana-Farber Cancer Institute
National Comprehensive Cancer Network
SIOF North America
St. Jude Children's Research Hospital

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Scan the QR Code below to get your Soapbox Schedule.





SCHEDULE OF EVENTS

TUESDAY, FEBRUARY 24

7:30am - 9:00am	Optional: Bereaved Parents Meet & Greet	Meeting Room 4
7:30am - 9:00am	Breakfast	Foyer Potomac Ballroom Salon 3
8:00am - 9:00am	Registration Opens	Foyer Potomac Ballroom Salon 3
9:00am - 3:00pm	Children's Activity Room (ages 5-12)	Meeting Room 2
9:00am - 3:00pm	Teen Program (ages 13-19)	Meeting Room 3

9:00am - 9:15am	Welcome to Action Days <ul style="list-style-type: none"> • Michael Link, MD., Alliance Co-Chair • Rosalie Abbott, Alliance Co-Chair 	Potomac Ballroom Salon 3
9:15am - 9:30am	What's Your 'Why?' (candlelighting at tables) <ul style="list-style-type: none"> • Danielle Leach, Principal, DDLeachConsulting 	Potomac Ballroom Salon 3
9:30am - 10:00am	NCI Research Update	Potomac Ballroom Salon 3
10:00am - 10:30am	DOD/PRCRP & ARPA-H Research Updates	Potomac Ballroom Salon 3
10:30am - 11:00am	Research Q & A - Panel Discussion	Potomac Ballroom Salon 3
11:00am - 11:15am	Break	
11:15am - 11:45am	Childhood Cancer Legislation Update <ul style="list-style-type: none"> • Accelerating Kids Access to Care Act Matthew Marks, Blood Cancer United • Mikaela Naylor Give Kids a Chance Act Nancy Goodman, Kids V. Cancer 	Potomac Ballroom Salon 3
11:45am - 12:30pm	Housekeeping & Group Photo	Potomac Ballroom Salon 3
12:30pm - 1:30pm	LUNCH	Foyer Potomac Ballroom Salon 3
1:30pm - 1:45pm	Navigating the Metro & Capitol Hill	Potomac Ballroom Salon 3
1:45pm - 2:45pm	How to Share Your Story - Panel Discussion <ul style="list-style-type: none"> • Danielle Leach, Moderator • Kassandra Naylor, Mother to Mikaela Naylor • Logan Shenker, Survivor, Medulloblastoma • Mary Petriccione, MSN, RN, PPCNP-BC, APP Pediatric Neuro-Oncology 	Potomac Ballroom Salon 3
2:45pm - 3:00pm	Soapbox	Potomac Ballroom Salon 3
3:00pm - 3:15pm	Children & Teens rejoin their families Move to State Tables	
3:15pm - 4:00pm	State Role Play & Hill Meeting Coordination* <ul style="list-style-type: none"> • *Mandatory 	Potomac Ballroom Salon 3 Meeting Room 4
4:00pm - 5:00pm	Informal Networking with Alliance Members	Potomac Ballroom Salon 3

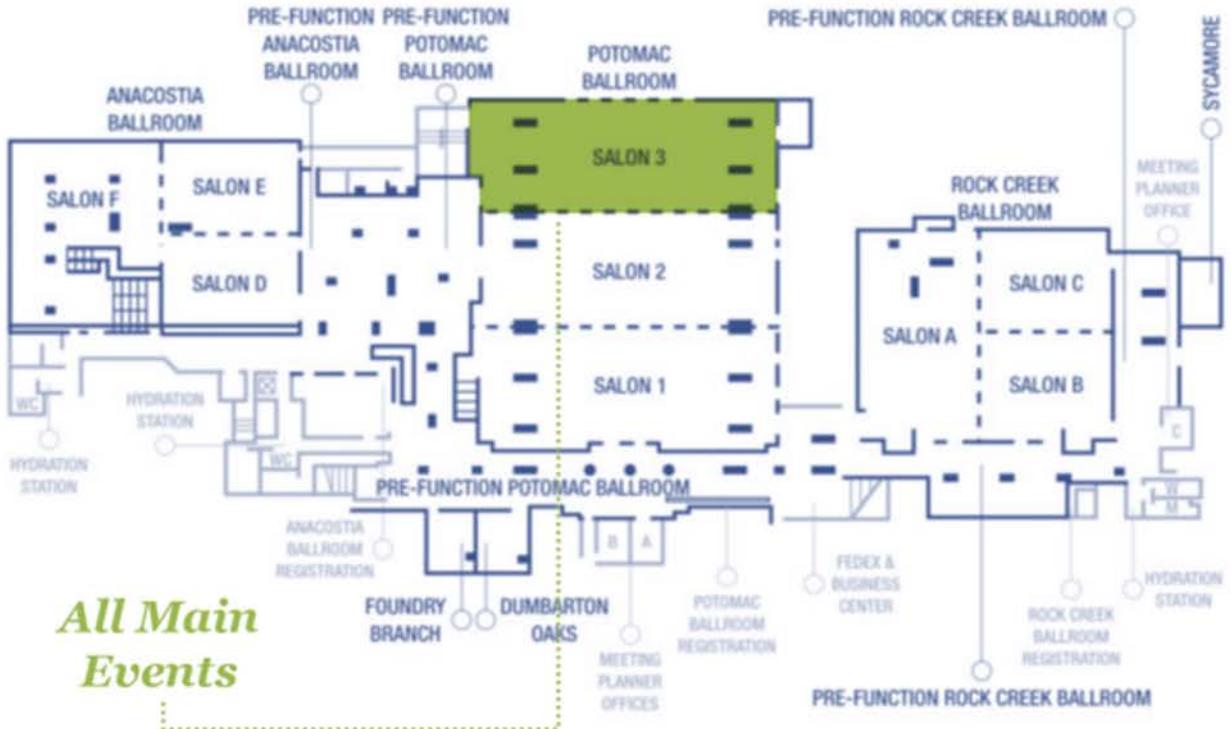
Dinner on your own.

WEDNESDAY, FEBRUARY 25

7:30am	Breakfast - <i>on your own</i>	Metro Gallery Place/Chinatown Station
8:30am	Depart for Capitol Hill via Metro	Capitol Hill
9:00am - 5:00pm	Capitol Hill Meetings	

WESTIN SITE MAP

BALLROOM LEVEL



All Main Events



Breakout Sessions

RESEARCH UPDATES

For children with cancer, federally funded intramural and extramural research is the doorway to new, less toxic treatments. Due to the smaller patient populations, drug companies do not have as strong an incentive to invest in new childhood cancer research and development as they do for their adult counterparts. The status quo often favors existing childhood cancer treatments, despite their long-term health impacts. As a result, the onus is on the federal government to fill the gap.

Research institutions and universities around the country rely on grants from the **National Institutes of Health (NIH)** and the **National Cancer Institute (NCI)**, funded by Congress, to find new discoveries, treatments, and cures. The critical and innovative intramural research being done on campus at NIH and NCI has saved countless lives and must continue to be fully funded and unimpeded in its mission to improve the lives of childhood cancer patients, survivors, and families.

The **Childhood Cancer Survivorship, Treatment, Access, Research (STAR) Act** is the most comprehensive and successful childhood cancer bill ever passed and reauthorized by Congress. It expands opportunities for childhood cancer research, improves efforts to identify and track incidences of childhood cancer and enhances the quality of life for childhood cancer survivors.

The programs authorized under the Childhood Cancer STAR Act serve as the critical infrastructure that makes childhood cancer research possible. Reauthorized every five years, the landmark legislation provides targeted investments to bolster childhood cancer survivorship research and expedite the discovery of new, less toxic treatments for the thousands of children who receive a cancer diagnosis each year.

The **Childhood Cancer Data Initiative (CCDI)** seeks to ensure that researchers learn from every child with cancer. The program enhances childhood cancer care and research data to improve preventive measures, treatment, quality of life, and survivorship. By building a community centered around childhood cancer care and research data, CCDI is making data more accessible for researchers and fast-tracking advances for children with cancer. With a primary goal of gathering data from every child, adolescent, and young adult diagnosed with a childhood cancer, CCDI is benefiting children diagnosed with cancer today and will lead to meaningful discoveries in the years to come. **On September 30, 2025, President Trump signed an Executive Order, doubling the CCDI budget from \$50 million to \$100 million to enable the use of artificial intelligence in the study of childhood cancer.**

Since 2009, the Department of Defense's **Peer Reviewed Cancer Research Program (PRCRP)** has supported innovative research in cancers designated by Congress as relevant to those in military service and their families. Childhood cancer, the leading disease killer of children, adolescents, and young adults (AYAs) in the United States, affects families without prejudice regardless of geographical location, occupation, or income and impacts the military readiness of our service men and women. Childhood, adolescent, and young adult cancers differ in biology and types from older adults and, therefore, require targeted research. The lives of many children, adolescents, and young adults depend on vigorous and innovative research programs like PRCRP to enhance understanding of these deadly tumors and discover new treatments that are more effective and less toxic. Each year, the Alliance advocates for **Congress to include pediatric, AYA cancers, pediatric brain tumors, neuroblastoma, sarcomas, germ cell cancers, blood cancers, lymphoma, and thyroid cancer as eligible funding topics under the program.**

The **Advanced Research Projects Agency for Health (ARPA-H)** is an agency that works to accelerate better health outcomes by funding high-potential, high-impact biomedical and health research that cannot be readily accomplished through traditional research.

Recently, ARPA-H announced a \$50 million project to scale a national pediatric data and knowledge network to improve outcomes for children with complex diseases—starting with pediatric brain cancer. The project, called Pediatric Care eXpansion (PCX), will connect more than 200 pediatric hospitals and care centers to securely exchange clinical and research data across the institutions—so clinicians can act on a more complete, usable picture of a child's care.



ACCELERATING KIDS' ACCESS TO CARE ACT (AKACA)



Every child facing a health crisis deserves access to the treatment they need. However, many children live in states where specialized care or a clinical trial is not available locally. Even some states with leading medical centers lack health providers with expertise in rare conditions. As a result, children with complex medical needs like cancer often must travel outside their states to receive treatment.

More than half of children in the U.S. rely on Medicaid and the Children's Health Insurance Program (CHIP) for their health insurance coverage. But bureaucratic rules often limit kids' ability to get timely treatment outside their home state. Today, if a child's condition requires treatment from an out-of-state provider, that child's entire care team must go through a lengthy enrollment process with the child's home state Medicaid program. This paperwork can take months, needlessly resulting in delays in treatment that can cause a child's condition to worsen. For children facing a cancer diagnosis or relapse, every minute matters.

The Accelerating Kids' Access to Care Act addresses these delays by allowing pediatric providers to enroll more efficiently in multiple state Medicaid programs, allowing them to provide essential, time-sensitive care to children who need it.

About Mason Duncan-Baski:

Mason was diagnosed with T-Cell Acute Lymphoblastic Leukemia at age nine. While being treated at Children's Hospital of Los Angeles, his family learned he qualified for a clinical trial at Texas Children's Hospital in Houston. Their insurance, Medi-Cal, would not cover out-of-state care. With Mason's life on the line, his parents enrolled him in the trial anyway, relying on their community's generosity through a GoFundMe. Sadly, the treatment was not successful, and Mason passed away at home, surrounded by his family. He urged his family to keep fighting for other kids with cancer.

MIKAELA NAYLON GIVE KIDS A CHANCE ACT OF 2025



SEC 2 OF GIVE KIDS A CHANCE ACT, HR 1262, GIVE KIDS A CHANCE ACT COMBINATION THERAPIES:

Provides the FDA with authority to direct pediatric cancer trials for combination drugs when the drugs are owned by the same company or are generics. Combinations have been demonstrated to be the best chance of new cures for kids with cancer. This provision is from the Give Kids a Chance Act, HR 3433 of the 118th Congress.

SEC 5 OF HR 1262, REAUTHORIZATION OF RARE PEDIATRIC PRIORITY REVIEW VOUCHER PROGRAM:

Through FY 2029 to incentivize the development of drugs for rare pediatric diseases. This program has expired despite bringing 60 new drugs for kids to market. This provision is from the Creating Hope Reauthorization Act, HR 7384, of the 118th Congress.

SEC 3 OF HR 1262, INNOVATION IN PEDIATRIC DRUGS ACT:

Provides the FDA the same authority to enforce against companies that do not complete their pediatric study requirements as the FDA has to enforce against companies that do not complete other post market study requirements. This provision is from part of the Innovation in Pediatric Drugs Act, HR 6664, of the 118th Congress.

SEC 7 OF HR 1262, PEDIATRIC DRUG STUDIES:

Report language that directs \$25,000,000 from an already-designated NIH fund be used to study pediatric drugs.

About Mikaela Naylon:

Mikaela was a glorious, brilliant 16 year old girl who for years advocated for the Give Kids a Chance Act. She last came to DC in September 2024 as part of the Climb the Hill Day, even though she was very sick.

A month later, as Mikaela approached her last days, Congressman Michael McCaul promised her that the Act would be renamed in her honor.

The Give Kids a Chance Act remembers Mikaela and all children who have fought pediatric cancer.

REQUESTS FOR CONGRESS



ASK 1: THANK YOU FOR PRIORITIZING KIDS

This year, Congress passed the Accelerating Kids' Access to Care Act and the Mikaela Naylor Give Kids a Chance Act into law! These two policies, which address some of the most pressing needs related to pediatric drug development, clinical trials, and access to care, represent the most influential childhood cancer legislation since the passage of the original Childhood Cancer STAR Act in 2018. This is a huge victory for the childhood cancer community and a tremendous show of support from our congressional champions.

Thank you for supporting the Accelerating Kids' Access to Care Act and the Mikaela Naylor Give Kids a Chance Act!

ASK #2: INCREASE FEDERAL FUNDING FOR CHILDHOOD CANCER RESEARCH IN FY27

Children with cancer rely on stable, federally funded research to discover new, less toxic treatments. Due to smaller patient populations, drug companies do not have as strong an incentive to invest in new childhood cancer treatments and cures as they do for adults. As a result, grants from the National Institutes of Health (NIH) and the National Cancer Institute (NCI) awarded to research institutions around the country must fill the gap. Support from the NIH also funds the critical research infrastructure that makes nearly all childhood cancer research possible, and programs like the Advanced Research Projects Agency for Health (ARPA-H) ensure that innovative ideas are quickly developed and implemented.

Last year, both Congress and the Administration made important progress towards increasing Federal support for childhood cancer research. In Fiscal Year 2027 (FY27), Congress must build on this progress by providing robust increases for the critical childhood cancer research programs that children with cancer and their families rely on.

The Alliance for Childhood Cancer urges Congress to provide:

- At least \$35 million for the Childhood Cancer STAR Act, a \$5 million increase, matching the funding provided in the FY26 House Labor-HHS-Education appropriations bill;
- \$100 million for the Childhood Cancer Data Initiative (CCDI), matching the total funding level provided by Congress in FY26 and the Executive Order signed by President Trump on September 30th, 2025, doubling the program's budget to enable the use of artificial intelligence in the study of childhood cancer;
- \$51.3 billion for the National Institutes of Health and \$7.9 billion for the
- National Cancer Institute; and
- \$1.5 billion for the Advanced Research Projects Agency for Health (ARPA-H).

SHARING YOUR STORY ON CAPITOL HILL

Tell your personal story and the impact childhood cancer has had on your life and why *it matters*.

Your voice makes the issue real.



PREPARING FOR YOUR MEETING

No conversation with a lawmaker or staffer follows a script – and that’s a good thing! This guide offers a framework to help you prepare, but the most powerful part of your meeting is your story. You bring these issues to life in a way no fact sheet ever could.

- Begin by introducing yourself and explaining why you’re there.

FOR EXAMPLE

“Congressman, I’m Julie McDonnell, and I live in your district in Springfield. I’m here today because childhood cancer is deeply personal to me. My child is a survivor but struggles daily with the late effects of toxic cancer treatments. I want to ensure children in the future have access to better treatment.”

Or, for a bereaved parent:

“Congressman, I’m Julie McDonnell from Springfield. I’m here because I lost my child to cancer because there wasn’t an effective cure. I want to ensure no other parent experiences this unimaginable loss.”

WHY WE’RE HERE

Cancer is the leading cause of disease-related death in children in the U.S. You have the power to change that.

We’re asking you to make childhood cancer a top national child health priority.



HOW TO BE AN EFFECTIVE CITIZEN ADVOCATE

DO'S

- **Be on time** – early is best! Meetings are short, so make every minute count.
- **Stay flexible** – congressional schedules often change.
- **Dress neatly and wear comfortable shoes** – you'll do plenty of walking.
- **Be polite and positive** – greet with a smile, handshake, and your full name.
- **Make a clear ask** – know your issue, share key facts, and request a specific action.
- **Be courteous** to everyone you meet.
- **Stay focused** – if you drift off-topic, pause and summarize your main point.
- **Share your story** – personalize the issue but always connect it back to the legislation.
- **Be honest** – if you don't know something, say so and promise to follow up.
- **Leave your information packet** at the end of the meeting.
- **Follow up** – we'll help you send thank-you notes and track progress afterward.

DON'TS

- **Don't lose your temper.** Stay calm and respectful at all times.
- **Don't go off-message** or discuss partisan politics.
- **Don't be late** or miss your scheduled meeting.
- **Don't make threats** - including about your vote.
- **Don't be discouraged** if your meeting is brief.
- **Don't underestimate a meeting with staff.** Every person in a congressional office – from interns to the Chief of Staff plays an important role. Building relationships with staff can be one of your strongest assets.

REMEMBER

Most public officials are happy when their constituents visit—they'll be friendly. Often, it's their favorite part of their job.



GETTING SOCIAL

Almost every member of Congress has an official Facebook, Bluesky, or X (*Twitter*) account, making these platforms powerful tools for constituents to drive action.

You can boost the impact of our Action Day meetings with a quick post on Facebook, Bluesky, or X. Snap a group photo at the end of your meeting – or a fun selfie – and don't forget to tag your elected officials using #ActionDays2026

SAMPLE POSTS

Proud to join with the Alliance for Childhood Cancer for #ActionDays2026 to urge my members of Congress to do their part for kids with cancer by passing childhood cancer legislation.

Advocates from across the country joined together today to ask **[insert ask here.]** I'm thrilled that I can count on **[legislator social media handle]** to show **[his/her]** support! #ActionDays2026

Today I asked **[legislator social media handle]** to **[insert ask here.]** #ActionDays2026

I'm urging **[legislator social media handle]** to give hope to childhood cancer patients, survivors, and families **[insert ask here.]** #ActionDays2026



SCAN HERE FOR LEGISLATOR TAGGING INFORMATION



IMPORTANT CONTACT INFORMATION

HOTEL INFORMATION

The Westin DC Downtown
999 9th St. NW, Washington DC, 20005
202-898-9000

CAPITOL HILL VISIT SCHEDULING CONCERNS

Soapbox Help Desk
202-362-5910

MEDICAL ISSUES CONTACT

Beth Siever, RN, MSN, CPNP, CPON
301-908-2578

ALLIANCE FOR CHILDHOOD CANCER

Email: actiondays@acco.org

HELPFUL WEBSITES

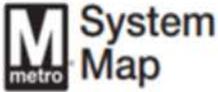
- Metro/Bus Service: wmata.com
- DC Tourist Info: washington.org
- Capitol Hill Map:
visitthecapitol.gov/visit
- Weather: wtop.com/weather/

CONGRESSIONAL INFORMATION

- Congress: congress.gov
- Senate: senate.gov
- House: house.gov



METRO MAP



wmata.com
 Information: 202-637-7000 | TTY: 202-962-2033
 Metro Transit Police: 202-962-2121 | Text: MYMTPD @96873

Legend

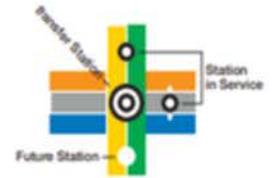
- Red Line • Glenmont / Shady Grove
- Orange Line • New Carrollton / Vienna
- Blue Line • Franconia-Springfield / Downtown Largo
- Green Line • Branch Ave / Greenbelt
- Yellow Line • Huntington / Greenbelt
- Silver Line • Ashburn / Downtown Largo

Station Features

- Parking
- Hospital
- Airport

Connecting Rail Systems

- A.M.T.C.
- MARC



Metro is accessible.

- No Smoking
- No Eating or Drinking
- No Animals (except service animals)
- No Audio (without earphones)
- No Littering or Spitting
- No Dangerous or Flammable Items

- The closest Metro station to the Westin is Gallery Place/Chinatown **RED** line
- The closest metro station to the Senate buildings is Union Station **RED** line
- The closest metro station to the House buildings is Capitol South **BLUE** line

CAPITOL HILL VISITOR INFORMATION

HOUSE OFFICE BUILDINGS

House office buildings along Independence Avenue, south of the Capitol, are named after Speakers of the House in alphabetical order, reflecting their terms in office. There are underground tunnels connecting each of the House Office Buildings.



1

CANNON HOUSE OFFICE BUILDING (CHOB)

has five floors. Room numbers have three digits, with the first digit designating floor level. Two-digit rooms preceded by a “B,” such as B74, are located in the basement.



2

LONGWORTH HOUSE OFFICE BUILDING (LHOB)

has seven floors. Room numbers have four digits beginning with 1. The number 1 indicates that the room is located in Longworth, the second digit indicates the floor level (0 indicates ground level). For example, 1126 is Longworth, first floor, room 26.

Rooms located in the basement and sub-basement levels have three digits, beginning with 2, and are preceded by the designation B or SB, for example B-217 LHOB.



3

RAYBURN HOUSE OFFICE BUILDING (RHOB)

has four floors. Room numbers have four digits beginning with 2. The number 2 indicates that the room is located in Rayburn; the second digit indicates the floor level (0 indicates ground level). For example, 2450 is Rayburn, fourth floor, office number 50.

Rooms located in the sub-basement levels have three digits beginning with the number 3 and are preceded by the designation B/SB respectively, followed by the number 3.

CAPITOL HILL VISITOR INFORMATION

SENATE OFFICE BUILDINGS

Senate office buildings along Constitution Avenue, north of the Capitol, honor distinguished U.S. Senators. There are underground tunnels connecting each of the Senate Office Buildings.



4

RUSSELL SENATE OFFICE BUILDING

has four floors. SR followed by three digits precedes room numbers in this building; the first digit indicates the floor level. SR followed by a B (for example, SRB103), precedes rooms located in the basement. This building connects to the Dirksen Senate Office Building through a tunnel on the basement level.



5

DIRKSEN SENATE OFFICE BUILDING

has six floors. SD followed by three digits precedes room numbers in this building; the first digit indicates the floor level. SD followed by G precedes rooms located on the ground level and rooms located on the basement level are preceded by SD followed by B. This building has connecting doorways on each floor to the Hart Senate Office Building. This building also connects to the Russell Senate Office Building through a tunnel on the basement level.



6

HART OFFICE BUILDING

has eight floors. Room numbers in this building are preceded by the designation SH followed by three digits; the first digit indicates the floor level. Rooms located in the basement are preceded by SH followed by B. The building has connecting doorways on each floor to the Dirksen Senate Office Building.

SPECIAL THANKS

TO OUR SPONSORS

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FOUNDATION

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Dana-Farber
Cancer Institute



Blood Cancer
United

SERVIER



GOLD BENEFACTOR



GOLD FRIEND





Comprehensive Cancer Care for Every Child, No Exceptions!

- Pediatric Oncology
- Benign Hematology
- Pediatric Rheumatology
- Family Genetics
- Pediatric Neuropsychology (Behavioral Health Center)
- Research & Clinical Trials
- LTFU Survivorship Program
- Specialty Infusion Services
- Pediatric Orthopedics
- Clinical & Supportive Pharmacy Services

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Learn more:



CURE 4 THE KIDS
FOUNDATION
Childhood Cancer & Rare Disease Center



Our focus is **oncology** but our priority is **patients**



Every decision our organization makes has the **patient in mind**.
The **patient voice** is an essential pillar of our organization.

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