# Testimony of Ellyn Miller President and Founder, Smashing Walnuts Foundation Before the Energy and Commerce Subcommittee on Health Enhancing Public Health: Legislation to Protect Children and Families October 20, 2021

Chairwoman Eshoo, Ranking Member Guthrie, and members of the Subcommittee, my name is Ellyn Miller, and I want to thank you for the opportunity to testify today in support of passage of the Gabriella Miller Kids First Research Act 2.0, legislation sponsored by my hometown Congresswoman Jennifer Wexton of Virginia. I am very grateful to her and to the Members of this Committee for your shared leadership in working on a bipartisan basis to fight the scourge of pediatric cancer and childhood disease.

#### Introduction

When my daughter was only 9 years old, she was diagnosed with a terminal-upon-diagnosis brain cancer called diffuse intrinsic pontine glioma (DIPG). This is the same brain cancer that Neil Armstrong's daughter, Karen, died from in 1962. Sixty years later, our children diagnosed with this cancer are receiving the exact same ineffective treatment: radiation and a Phase I clinical trial.

In those 60 years, we have gotten men and women to the moon and safely back home. We have a rover on Mars. We can chart the meteors that will never enter our atmosphere and the deepest depths of our oceans. But we can't solve something a few inches under our skin?

In the 1980s, AIDS was a death sentence. Today, it is a chronic disease. A handful of years ago Ebola was also a death sentence. Now it is curable. We, as a country, can claim these incredible accomplishments because we banded together to make them a national priority. We must make our children that are battling cancer and other childhood diseases a national priority as well. We all recognize the special tragedy of a life cut short in childhood or adolescence, and that we as adults owe a special reasonability to prevent harm to children. This legislation helps us keep that commitment.

#### Background

After my daughter died, I worked to learn as much as I could about childhood cancer. I have learned that the rate of childhood and adolescent cancer has steadily risen since 1975. From 2014 to 2018, an average of 47 kids were diagnosed with cancer every day – that is over 17,000

<sup>&</sup>lt;sup>1</sup> Childhood cancer is typically defined as cancer occurring between ages 0-19. *See, e.g.*, National Institutes of Health: National Cancer Institute (NCI), Cancer in Children and Adolescents, https://www.cancer.gov/types/childhood-cancers/child-adolescent-cancers-fact-sheet (last updated Apr. 20, 2021).

<sup>&</sup>lt;sup>2</sup> See American Cancer Society, Cancer Facts & Figures: 2021 (2021), <a href="https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2021/cancer-facts-and-figures-2021.pdf">https://www.cancer.org/content/dam/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2021/cancer-facts-and-figures-2021.pdf</a>.

children per year.<sup>3</sup> This year, an estimated 1,780 children will die from cancer.<sup>4</sup> More children are lost to cancer in the U.S. than to any other disease.<sup>5</sup>

I have also learned that while dozens of new cancer therapies have been introduced over the last several decades, there are very few treatments that are specifically designed to treat pediatric cancer. As of 2020, only six drugs have received FDA approval in the first incident of cancer treatment for children.<sup>6</sup> None of these drugs treat pediatric brain cancer. Survivors of childhood cancer often suffer long-term health consequences due to the side effects of the treatment regimens available today. More than 95 percent of childhood cancer survivors will experience a significant health-related issue by the time they are 45 years of age – not only due to their illness, but also due to the lack of available treatments.<sup>7</sup>

The lack of pharmaceutical company involvement leaves the government and private charities as the main backers of childhood cancer research. But only 4 percent of the National Cancer Institute's budget is specifically allocated to childhood cancer research.<sup>8</sup> Pediatric oncologists lack funding for important research and can struggle to get access to promising drugs.

#### The Gabriella Miller Kids First Research Act

Recognizing the need for additional resources to meet this challenge, Congress worked on a bipartisan basis to pass the Gabriella Miller Kids First Research Act, enacted in 2014<sup>9</sup> – landmark legislation that opened the door to new avenues of research through significant federal investments in the fight against childhood cancer and disease.. Then-House Majority Leader Eric Cantor was so moved by Gabriella's activism in the face of terminal cancer that he named legislation after her. The Act shifted funding that was previously allocated for political conventions to pediatric disease research. It was signed into law less than six months after Gabriella's death.

The Act also established a ten-year Pediatric Research Initiative Fund and authorized \$12.6 million in annual funds for childhood disease research through Fiscal Year 2023. It led to the creation of the National Institute of Health's Kids First Pediatric Research Program and Data Resource Center and has allocated millions of dollars to research grants looking into pediatric cancer, supporting over 60 research projects [Appendix 1].<sup>10</sup>

<sup>&</sup>lt;sup>3</sup> Calculated from NCI, Age-Adjusted and Age-Specific SEER Cancer Incidence Rates, 2014-2018, Table 2.1 (Apr. 15, 2021), <a href="https://seer.cancer.gov/csr/1975">https://seer.cancer.gov/csr/1975</a> 2018/results <a href="mailto:single/sect\_02\_table.01\_2pgs.pdf">single/sect\_02\_table.01\_2pgs.pdf</a>.

<sup>&</sup>lt;sup>4</sup> Rebecca Siegel, et al., *Cancer Statistics*, 2021, 71 CA Cancer J. for Clinicians 7 (2021).

<sup>&</sup>lt;sup>5</sup> See Cancer in Children and Adolescents, supra note 1.

 $<sup>^6</sup>$  See NCI, Drugs Approved for Childhood Cancers, <a href="https://www.cancer.gov/about-cancer/treatment/drugs/childhood-cancer-fda-approved-drugs?cid=eb\_govdel">https://www.cancer.gov/about-cancer/treatment/drugs/childhood-cancer-fda-approved-drugs?cid=eb\_govdel</a> (last updated Aug. 18, 2021).

<sup>&</sup>lt;sup>7</sup> Melissa Hudson, et al., *Clinical Ascertainment of Health Outcomes Among Adults Treated for Childhood Cancer*, 309 JAMA 2371 (2013).

<sup>&</sup>lt;sup>8</sup> See NCI, NCI Funded Research Portfolio, <a href="https://fundedresearch.cancer.gov/nciportfolio/">https://fundedresearch.cancer.gov/nciportfolio/</a> (last accessed Oct. 16, 2021).

<sup>&</sup>lt;sup>9</sup> The Gabriella Miller Kids First Research Act, Pub.L. 113–94 (2014) (codified at 42 U.S.C. 282(b)).

<sup>&</sup>lt;sup>10</sup> NIH: Office of Strategic Coordination – The Common Fund, Gabriella Miller Kids First: Funded Research, https://commonfund.nih.gov/kidsfirst/fundedresearch (last reviewed Sept. 9, 2021).

The Kids First program at NIH helps researchers discover new insights into the biology of childhood cancer and other pediatric disorders. The Data Resource Center has focused on building a large-scale database for both clinical and genetic data from kids with cancer, with the goal of finding patterns that will accelerate research into cures and less harsh treatments. Currently, over 25,000 samples have been genetically sequenced to promote new scientific discoveries.<sup>11</sup>

#### The Gabriella Miller Kids First Research Act 2.0

As you can see, the Gabriella Miller Kids First Research Act opened the door for many new opportunities. We applaud what Congress has done, and we're grateful to this committee for its bipartisan support. The Act setting an amazing foundation for work that still needs to be done. As the initial funding period approaches its close, it especially important we continue to find a way to fund all of the incredible work researchers are doing in this space.

We're asking this committee to move the ball forward. Building on our shared progress to date, the Gabriella Miller Kids First Research Act 2.0 will take us to the next level in the fight. Kids First 2.0 proposes a new method to fund childhood cancer research: take money away from companies that behave badly and use it to pay for desperately needed pediatric disease research.

The bill was introduced in the House by Representative Jennifer Wexton. It has had bipartisan support in this Committee, with 21 co-sponsors, and enjoys bipartisan support in the House and the Senate, with over 70 representatives and 7 senators co-sponsoring. The bill would institute a new, stable and robust source of funding for the Kids First program. Specifically, it would redirect money from penalties paid by pharmaceutical, cosmetic, supplement, and medical device companies found in violation of the Foreign Corrupt Practices Act<sup>12</sup>, or FCPA. The Kids First Act 2.0 would require the Secretary of the Treasury to transfer these funds directly into the Pediatric Research Initiative Fund established by the original Act. This legislation would allow the government to fund an important cause without taking money away from the NCI.

Channeling fines or penalties into a dedicated program fund is nothing new. Congress has been doing this for many years. For example, the Federal Hospital Insurance Trust Fund, which funds Medicare Part A, receives civil penalties from violations of the False Claims Act and criminal fines and forfeitures from violations of the Federal Food, Drug, and Cosmetic Act. And, once collected, the Secretary of the Treasury transfers a wide range of criminal fines into the Crime Victims Fund, including criminal fines collected in FCPA cases. This bill uses a source of funding that has yet to be dedicated: civil FCPA penalties. The Gabriella Miller Kids First Act 2.0 proposes to use this untapped resource to make a difference in the battle against childhood cancer – to work towards the goal of accomplishing Gabriella's dream.

<sup>&</sup>lt;sup>11</sup> Gabriella Miller Kids First Research Program: Data Resource Center, <a href="https://kidsfirstdrc.org/">https://kidsfirstdrc.org/</a> (last accessed Oct. 16, 2021).

<sup>&</sup>lt;sup>12</sup> 5 U.S.C. §§ 78dd-1, et seq.

<sup>&</sup>lt;sup>13</sup> 42 U.S.C. § 1395i.

<sup>&</sup>lt;sup>14</sup> 34 U.S.C. § 20101.

#### Conclusion

Before she died, Gabriella recorded a video. When asked what she wanted elected officials to do about childhood cancer, she stated "stop talking and start doing." This committee has already stepped up to answer Gabriella's call once – I ask that you do that once more. I ask that this committee to proceed through markup and to move this critical piece of legislation to the floor as swiftly as possible.

A letter of support [Appendix 2] to the House and Senate for this new bill garnered signatures from over 300 foundations and organizations [Appendix 3] and more than 1,400 advocates from all 50 states [Appendix 4]. The Alliance for Childhood Cancer also submitted a letter in support of this legislation [Appendix 5]. My daughter's name is on this legislation but, in reality, it could be any number of the hundreds of thousands of children afflicted with cancer and disease across the country. Thank you for the opportunity to submit this testimony to the subcommittee.

#### Appendix 1 NIH Gabriella Kids First Pediatric Research Program: Funded Research

PI Name	Institution Name	State	Title		
	2021				
Cody, Jannine De Mars	University of Texas Health Science Center	Texas	The Genomic Basis of Structural Birth Defects Associated with Chromosome 18 Copy Number Changes		
Diskin, Sharon	Children's Hospital of Philadelphia	Pennsylvania	The Genetic Basis Of Treatment Outcomes And Late Effects After High-Risk Neuroblastoma		
Gelb, Bruce D	Icahn School of Medicine at Mount Sinai	New York	Expanding Our Understanding Of The Role Of Noncoding Variation Causing Congenital Heart Defects		
Krantz, Ian D	Children's Hospital of Philadelphia	Pennsylvania	Rnaseq In Cornelia De Lange Syndrome, Related Diagnoses And Structural Birth Defects		
Letra, Ariadne M	University of Texas Health Science Center Houston	Texas	Whole Genome Sequencing Studies Of Multiplex Nonsyndromic Cleft Lip/Palate Families		
Lupo, Philip J	Baylor College of Medicine	Texas	Genetic Overlap Between Anomalies And Cancer In Kids In The Childrens Oncology Group: The COG GOBACK Study		
Meshinchi, Soheil	Fred Hutchinson Cancer Research Center	Washington	Germline And Somatic Variants In Pediatric AML		
Resnick, Adam Cain	Children's Hospital of Philadelphia	Pennsylvania	Germline And Somatic Disease Modifiers Of Pediatric Brain Tumors		
Scheurer, Michael E	Baylor College of Medicine	Texas	Genomic Analysis Of Histiocytosis		
Shlien, Adam	Hospital For Sick Children (Toronto)	Ontario (Canada)	Discovering The Timing And Origins Of Bone And Soft Tissue Cancers		
		2020	1		
Chung, Wendy K (contact); Shen, Yufeng	Columbia University Health Sciences	New York	Genomic Analysis of Congenital Diaphragmatic Hernia and Associated Congenital Anomalies		

PI Name	Institution Name	State	Title
Marazita, Mary L. (contact); Feingold, Eleanor	University of Pittsburgh at Pittsburgh	Pennsylvania	Kids First: Genomics of Orofacial Cleft Birth Defects in Latin American Families
Weaver, Kathryn	Cincinnati Children's Hospital Medical Center	Ohio	Genetic diagnoses in a cohort of individuals with valvar pulmonary stenosis
Gabriel, Stacey	Broad Institute, Inc.	Massachusetts	Genome Sequencing in support of the Gabriella Miller Kids First Pediatric Research Program
Levy, Shawn E (contact); Zhang, Jinghui	Hudson-Alpha Institute for Biotechnology	Alabama	Characterizing pediatric genomes through an optimized sequencing approach
		2019	
Chung, Wendy K (contact); Shen, Yufeng	Columbia University Health Sciences	New York	Genomic Analysis of Esophageal Atresia and Tracheoesophageal Fistulas and Associated Congenital Anomalies
Gharavi, Ali G	Columbia University Health Sciences	New York	Whole Genome Sequencing in Congenital Anomalies of the Kidney and Urinary Tract
Gleeson, Joseph	University of California, San Diego	California	Whole Exome, Genome, and RNA Sequencing in Recessive Structural Brain Defects in Children
			Whole Exome and Genome Sequencing in Structural Defects of the Neural Tube
Lesile, Elizabeth	Emory University	Georgia	Genomics of Orofacial Clefts in the Philippines
Lupo, Philip J (contact); Plon, Sharon E.	Baylor College of Medicine	Texas	Genomic Analysis of Pediatric Rhabdomyosarcoma
Martin, Donna	University of Michigan at Ann Arbor	Michigan	Genomic Etiologies of CHARGE Syndrome, Related Conditions and Structural Anomalies
Teachy, David	Children's Hospital of Philadelphia	Pennsylvania	Comprehensive Genomic Profiling to Improve Prediction of Clinical Outcome for Children with T-cell Acute Lymphoblastic Leukemia

PI Name	Institution Name	State	Title
Ware, Stephanie	Indiana University - Purdue University at Indianapolis	Indiana	Genomic Analysis of Laterality Birth Defects
		2018	
Chambers, Christina	University of California, San Diego	California	Discovery of Genetic Basis of Fetal Alcohol Spectrum Disorders
Chung, Wendy K (contact); Shen, Yufeng	Columbia University Health Sciences	New York	Genomic Analysis of Esophageal Atresia and Tracheoesophageal Fistulas and Associated Congenital Anomalies
Drolet, Beth A	Medical College of Wisconsin	Wisconsin	Analyzing the Genetic Spectrum of Vascular Anomalies, Overgrowth and Structural Birth Defects
Gharavi, Ali G (contact); Wong, Craig S	Columbia University Health Sciences	New York	Genetics of Structural Defects of the Kidney and Urinary Tract
Jelin, Angie Child	Johns Hopkins University	Maryland	Single gene pathogenic variants associated with BEEC (Bladder extrophy, Epispadias, Complex)
Krantz, Ian D	Children's Hospital of Philadelphia	Pennsylvania	Genomic Diagnostics in Cornelia de Lange Syndrome, Related Diagnoses and Structural Birth Defects
Lau, Ching Ching (contact); Poynter, Jenny N.	Jackson Laboratory	Connecticut	Genetic Predisposition to Intracranial Germ Cell Tumors
Lupo, Philip J (contact); Rabin, Karen R; Sherman, Stephanie L.; Yang, Jun J	Baylor College of Medicine	Texas	Genomic Analysis of Congenital Heart Defects and Acute Lymphoblastic Leukemia in Children with Down Syndrome
Meshinchi, Soheil	Fred Hutchinson Cancer Research Center	Washington	Germline and Somatic Variants in Myeloid Malignancies in Children
Seidman, Christine E	Harvard Medical School	Massachusetts	Somatic and Germline Mutations in CHD
Seidman, Jonathan G	Harvard Medical School	Massachusetts	The Genetics of Microtia in Hispanic Populations

PI Name	Institution Name	State	Title
		2017	
Boyadjiev Boyd, Simeon A (contact); Romitti, Paul A	University of California Davis	California	Whole Genome Sequencing of Nonsyndromic Craniosynostosis
Butali, Azeez (contact); Beaty, Terri H.	University of Iowa	Iowa	Whole Genome Sequencing of African and Asian Orofacial Clefts Case-Parent Triads
Chung, Wendy K (contact); Shen, Yufeng	Columbia University Health Sciences	New York	Genomic Analysis of Congenital Diaphragmatic Hernia and Associated Congenital Anomalies
Hakonarson, Hakon (contact); Resnick, Adam Cain; Sleiman, Patrick Martin	Children's Hospital of Philadelphia	Pennsylvania	Genetics at the Intersection of Childhood Cancer and Birth Defects
Luquetti, Daniela Varela	University of Washington	Washington	Craniofacial Microsomia: Genetic Causes and Pathway Discovery
Schiffman, Joshua David	University of Utah	Utah	Expanded Ewing Sarcoma Cohort for Tumor Genomics and Association with DNA Repair Deficiencies, Clinical Presentation, and Outcome
Siegel, Dawn H	Medical College of Wisconsin	Wisconsin	Genomic Analysis of a Cohort with Infantile Hemangiomas Associated with Multi-Organ Structural Birth Defects
Sobreira, Nara	Johns Hopkins University	Maryland	Genome-wide Sequencing to Identify the Genes Responsible for Enchondromatoses and Related Malignant Tumors
Resnick, Adam Cain (contact); Davis-Dusenbery, Brandi Nicole; Ferretti, Vincent; Grossman, Robert L.; Hakonarson, Hakon; Kural, Deniz; Margolin, Adam Arne; Stein, Lincoln D; Taylor, Deanne Marie; Volchenboum, Samuel	Children's Hospital of Philadelphia	Pennsylvania	Innovation Through Collaboration at the Intersection Of Childhood Development and Cancer: A Platform for the Gabriella Miller Kids First Pediatric Data Resource Center

PI Name	Institution Name	State	Title	
2016				
Chung, Wendy K (contact); Shen, Yufeng	Columbia University Health Sciences	New York	Genomic Analysis of Congenital Diaphragmatic Hernia and Associated Congenital Anomalies	
Marazita, Mary L. (contact); Feingold, Eleanor	University of Pittsburgh at Pittsburgh	Pennsylvania	Kids First: Genomics of Orofacial Cleft Birth Defects in Latin American Families	
Maris, John M	Children's Hospital of Philadelphia	Pennsylvania	Genetic Basis of Neuroblastoma Initiation And Progression	
Mullighan, Charles G (contact); Metzger, Monika; Nichols, Kim Erika; Sandlund, John; Yang, Jun J	St. Jude Children's Research Hospital	Virginia	Genomic analysis of familial leukemia	
Plon, Sharon E.	Baylor College of Medicine	Texas	Identifying Novel Cancer Susceptibility Mutations from Unselected Childhood Cancer Patient and Parent Trios	
Rios, Jonathan	UT Southwestern Medical Center	Texas	Genomics of Orthopaedic Disease Program	
Seidman, Christine E.	Harvard Medical School	Massachusetts	Discovery of De Novo and Inherited Mutations that Cause Prevalent Birth Defects	
Shen, Jun (contact); Morton, Cynthia Casson	Brigham And Women's Hospital	Massachusetts	Hear-n-Seq: Sequencing Kids First for Hearing	
Gabriel, Stacey	Broad Institute, Inc.	Massachusetts	Genome Sequencing in support of the Gabriella Miller Kids First Pediatric Research Program	
Levy, Shawn E (contact); Zhang, Jinghui	Hudson-Alpha Institute For Biotechnology	Alabama	Characterizing pediatric genomes through an optimized sequencing approach	
	'	2015		
Chung, Wendy K.	Columbia University Health Sciences	New York	Genomic Analysis of Congenital Diaphragmatic Hernia	
Engle, Elizabeth C.	Children's Hospital Corporation	Massachusetts	BCH Structural Birth Defects Collaboration: Syndromic Cranial Dysinnervation Disorders	

PI Name	Institution Name	State	Title
Marazita, Mary L.	University of Pittsburgh	Pennsylvania	Genomic Studies of Orofacial Cleft Birth Defects
Onel, Kenan	The University of Chicago	Illinois	An Integrated Clinical and Genomic Analysis of Treatment Failure in Pediatric Osteosarcoma
Schiffman, Joshua David	University of Utah	Utah	Genetic Contribution to Ewing Sarcoma in 330 parent-Offspring Trios
Seidman, Christine E.	President and Fellows of Harvard College	Massachusetts	Discovery of the Genetic Basis of Structural Heart and Other Birth Defects
Vilain, Eric	University of California Los Angeles	California	Genetic Basis of Disorders/Differences of Sex Development (DSD)
Gibbs, Richard A	Baylor College of Medicine	Texas	The Human Genome Sequencing Center
Wilson, Richard K	Washington University	Washington	A Platform for Large-Scale Genomic Discovery

#### Appendix 2 Letter of Support for the Gabriella Kids First Research Act 2.0

### Letter of Support for

Gabriella Miller Kids First Research Act 2.0

H. R. 623



The Honorable Jennifer Wexton US House of Representatives 1217 Longworth House Office Building Washington, DC 20515

The Honorable Peter Welch US House of Representatives 2187 Rayburn House Office Building Washington, DC 20515 The Honorable Tom Cole US House of Representatives 2207 Rayburn House Office Building Washington, DC 20515

The Honorable Gus Bilirakis US House of Representatives 2227 Rayburn House Office Building Washington, DC 20515

Re: H.R. 623 - The Gabriella Miller Kids First Research Act 2.0

Dear Ms. Wexton, Mr. Cole, Mr. Welch, and Mr. Bilirakas.

The undersigned organizations and advocates are writing in full support of H.R. 623 - The Gabriella Miller Kids First Research Act 2.0. Each year, approximately 16,000 children are diagnosed with childhood cancer and thousands more are diagnosed with rare disease. Childhood cancers and adult cancers are not the same. Chemotherapies are designed to kill the fastest growing cells (cancer) in an adult's body. Due to a lack of research, and the fact that only four child-appropriate drugs are available, most children have to rely on adult cancer drugs and therapies. Chemotherapy used on children also kills fast-growing cells, but that is the major problem, because all cells in a child's heart, bones, body, and vital organs are fast growing. Survivors of childhood cancer are at a 15-fold increased risk of developing congestive heart failure and six times more likely than the general population to be diagnosed with breast cancer later in life. Today, there are over 500,000 childhood cancer survivors in America and more than two-thirds will have serious, life-threatening health issues before age fifty.

According to the National Cancer Institutes' NCI Funded Research Portfolio, from 2007 until 2018, only 4.08% of the NCI budget was used for childhood cancer research.

In 2014, Congress passed the Gabriella Miller Kids First Research Act which established the Ten Year Pediatric Research Initiative Fund and authorized \$12.6 million in annual funds for childhood disease research, including important areas of emerging scientific opportunities, rising public health challenges, and knowledge gaps. Since it was enacted, the bill has provided \$88 million to childhood cancer and disease research. It is expected to provide another \$38 million over the remaining three years.

As funding will expire in fiscal year 2023, <u>H.R. 623 - The Gabriella Miller Kids First Research Act 2.0</u> will provide a new and continuing source of funding for the Kids First Research Initiative Program. This new source of funding, which is expected to be exponentially larger, does not have an end date, is not supported with taxpayer funding, and is invaluable to consistently improve the outcomes of children fighting cancer and other rare diseases.

## Appendix 3 Foundations and Organizations Who Signed in Support of the Gabriella Kids First Research Act 2.0

1 Million 4 Anna Foundation	Batcole Foundation  Bear Necessities Pediatric	Cannes-N-Kids Foundation
1Voice Foundation	Cancer Foundation	Carson Leslie Foundation
3/32 Foundation	Beat Cancer Today, Inc.	Cash Hyde Foundation
4Another	Because of Daniel	Chabad of Loudon County
Addie's Tea Party	Benjamin's Hope for the Future	Children's Brain Tumor Foundation
Aidan's Avengers	Bite Me Cancer	Children's Cancer Cause
Alexa Nawrocki Pediatric Cancer Foundation, Inc.	Blaser Cancer Research	Chris Lantos Foundation
All In To Win Foundation	Fund	Cory's Project
Along Comes Hope	Braden's Hope For Childhood Cancer	Courtney's Courage
Always Dancing With Grace	BraveCort Foundation	Crowns Fight Cancer
American Childhood	Brennan's Buddies, Inc.	CURE Bears for Hope and Love
Cancer Organization	Brooke's Blossoming Hope for Childhood	Cure Kids Cancer Now
Angels for Change	Cancer	Dance Hope Cure
Ari's Bears	Bryanna's Love	Dawson's Circle of Hope
Arms Wide Open Childhood Cancer Foundation	Cal's All-Star Angel Foundation, Inc.	Declan's Army
	Caleb's Crusade for	Delaney Donates
Athletes Crush Cancer	Childhood Cancer	DIPG Advocacy Group
AYJ Fund	Camp Sunshine at Sebago Lake, Inc.	Dragon Master Foundation
Baby Jay's Legacy of Hope	Candlelighters Childhood	Dreaming of Axel
Bald Beauties Project	Cancer Foundation of	Ellie's Hats
Band of Parents	Southern Arizona	Elizabeth's Hope
	Candlelighters NYC	

Fighter Maverick / Maverick's Comfort Mission	Infinite Love for Kids Fighting Cancer	Lily LaRue Foundation DIPG
	IPromise 15	Liv Like a Unicorn
Finn's Fighters	Isabella's Journey	Love for Liberty Arnold-
Forever and a Day Foundation	Jack's Angels	Simon DIPG Foundation
Forever Lil	Jake's Dragon Foundation	Lucy's Lights
Four Square Clobbers	Joey's Wings Foundation	Luke's Posse: DIPG Ends Now
Cancer Friends of Emily	Johnny Volpe's Childhood Cancer Awareness Page	Mattie Miracle Cancer Foundation
Friends of the Voiceless	Jonathan Cancer Fund, Inc.	Max Cure Foundation
Gabriella's Smile	Journey4ACure	Maynard Childhood
Foundation	Julia's Grace Foundation	Cancer Foundation
Gage Overton Memorial Fund	Kate's Cause	Michael Mosier Defeat DIPG Foundation
Gamers for Children's Health	Kaylan Stronger Fight Like A Warrior Foundation	MikeyNation
Gianna's Force of Hope	Kegs and Corks for Kids	Miracle for Ryan
-	Cancer	Momcology
Gianna Nicole's Heart Of Hope	KIDS NEED MoRE	Moms Making Miracles
Gold In September (G9)	Kira Spedale Foundation	My Dog Named Hope, Inc.
Grace's Gold Ribbon Gang	Koenig Childhood Cancer Foundation	Mystic Force Foundation
Grandparents in Action	Kyle's Crusaders	Nevus Outreach, Inc.
Heroes for Hope	•	Nico's Army
HOPE FASTER	Kyle's Kamp  Kylie Rowand Foundation	Northwest Indiana Cancer Kids Foundation, Inc.
Hope For Gold Now	Lace 'Em Up for Libby	Off The Charts Club
Hope4ATRT		
Hugabox	Lily Chiquet Strength Foundation	Oncoheroes Biosciences
-		Open Hands Overflowing Hearts

Orange Ribbon Foundation	Smiley for Kylie, Inc.	The Chase Ryan Olsen Foundation
Osteosarcoma	Sophia's Fund	
Collaborative, Inc. Our Amazing Fighters	Spaeda Pediatric Sarcoma Foundation	The DIPG Advocacy Group
		The Kortney Rose
Our Amazing Owen	Step Sisters	Foundation
P.U.N.T. Foundation	Stillbrave	The Lilabean Foundation
Pediatric Brain Tumor Foundation	Strong Little Souls	The Matilda Project
Pediatric Cancer Awareness 24/7	Swirls Around the World Foundation	The Pediatric Compass Foundation, Inc.
	Talia's Legacy Children's	The Reflections of Grace
Pierce Phillips Charity	Cancer Foundation	Foundation
Praying for Caroline	Team Arnav Foundation	The Super Nova Project
Precious Jules Childhood Cancer Foundation	Team BT	The Taylor Matthews Foundation
	Team Colton DIPG	
Race for CHAnge	Foundation	The Truth 365
Rally for Ally	Team Cozzi Foundation	The Wes Strong Foundation
Rally Foundation for	Team Lucas	
Childhood Cancer Research	Team Sabrina	This Star Won't Go Out
Richi Childhood Cancer	The Alexander Muñoz	Tiny Dancer Project, Inc.
Foundation	Memorial Fund	Unravel Pediatric Cancer
Ryan Bartel Foundation	The Andrew McDonough	Foundation
•	B+ Foundation	Virginia Polar Dip
Ryan Homes	The Blue Lollipop Project	West Virginia Kids Cancer
SADD		Crusaders
Sadie Keller Foundation	The Brad Kaminsky Foundation	Wings for Ewing Sarcoma
Sara's Acts of Kindness	The Brooke Healey	Wonder Capes
SkiFast Foundation	Foundation	Wylie's Day Foundation
Smashing Walnuts	The ChadTough	
Smashing walluts	Foundation	You Are The Hero, Inc.

#### Appendix 4 Advocates (and Their States) Who Signed in Support of the Gabriella Kids First Research Act 2.0

Anne Abbott VA	Michelle Arnold VA	Theresa Beech MD
Colette Abramo NJ	Sam Atapour VA	Susan Beerman DE
Donna Abshire VA	Navid Attayan NC	Kevin Beezhold PA
Vanessa Accetturo FL	Paula Augenstein VA	Amanda Bekric MN
Rebecca Adams VA	Joe Baber VA	Emily Belcher VA
Matt Adams VA	Paili Bachrach IL	Tiffany Bell-Alanis OR
Wendy Addington MD	Mary Beth Bader NJ	Teodora Beloreshka IL
Jake Adler IL	Trista Baker VT	Wendy Benoit NY
Innocentia Afa VA	Tracy Banas PA	Tia Benyshek KS
Jonathan Agin VA	Anna Baratelle PA	Janine Betsey IN
Suhile Alami VA	Judy Barnes ID	Katherine Bigeagle OR
Vicki Albaugh IN	Lisa Barrett FL	Bailey Bindle NE
Alyssa Alber IL	Suzie Bartel VA	Carol Birch NY
Kristen Alexander CT	Jay Bartlett VA	Maddie Birk IL
Melissa Alexander VA	Carol Bartlett-Stewart NC	Laura Birnbaum IL
Chris Alexander CT	Sarah Bartosz WI	Kathleen Bisignano NJ
Ken Altshuler GA	Mary Barwick WI	Sheryl Blackington VA
Joshua Altshuler NJ	Carol Basso TX	Jana Blakey OK
Deanna Amoriello NJ	Mara Battaglia IL	Angela Blaser IL
Barbara Anderson NJ	Michele Batz IL	Emma Blaser IL
Monica Angel FL	Jennifer Baxa IL	Christine Bloom PA
Kathy Arabia MA	Mackenzie Beal PA	Debbie Boggess MT

Sharon Bolasny FL

Jeffrey Beard MI

Sara Arnold MA

Lisa Bolton OH	Laura Burnopp FL	Tara Castleberry KY
Delaney Bopp IA	Leah Burns TX	Abby Ceane IL
Hope Bott FL	Gina Buscetta NJ	Richelle Chapman FL
Isabelle Boullier RI	Victoria Bussey IL	Heather Charre TN
Mary Bowler CA	Aimee Cabral NJ	Ashish Chawla VA
Eric Bowman WV	Eileen Campagne TX	Cindy Chejfec IL
Aimee Boyd ID	Lindsay Campbell-	Premil Chery NY
Dina Bradford IL	Reidhead VA	Kelley Cheverino NJ
Rosni Bradley MD	Deb Campion CT	Michelle Chiquet CA
Kristen Brady CT	Kirk Campion CT	Michelle Church UT
Janet Braverman FL	Christopher Campo NY	Andrea Church CA
Laura Bray FL	Ashley Campolattaro VA	Emily Cleland VA
Brianna Brodak CO	Judy Cannedy LA	Danielle Cloakey WA
Cheryl Brooks VA	Allyson Capotorto NJ	Jay Coakley VA
Amanda Brooks TX	Robin Carlini FL	Stacey Coates IL
Ethlyn Brooks VA	Erin Carlucci NJ	Miriam Cohen MD
Peter Brown DC	Donna Carmical VA	Maria Cohen VA
Staci Buchholz IL	Wendy Caron NH	Yehudis Cohen VA
Robert Budlow NY	Melissa Carr MI	Cindi Colby VA
Kim Buff FL	Ashley Carrington FL	Shawn Collard WI
Paige Bulmer NY	Jennifer Caruso MA	Connie Colton FL
Jeannine Buono NJ	Caroline Casey IL	Salvatore Conigliaro NJ
Madisyn Burk IL	Stephanie Cassabria NJ	Ann Connors TX
Josephine Burke WY	Desiree Castellano FL	Maribeth Conroy MA
Emily Burke VA	Roxce Castillo VA	Courtney Conway MI
EIIIIIY BURKE VA	Jenica Castillo-Harden OR	Continey Conway Ivii

Lisa Cook VA Robert Davis VT Tamra Downing IL

Emily Cook MT Catherine Davis VT Jamie Drake UT

Bennett Corley TN Norma Davis VA Sara Draper WA

Dave Cormier NY Tiffany Dawson FL Carol Dugan CT

Paul Cozzi WA Joe Dean WI Christine Dugdell VA

Cynthia Cozzi WA Shela Dean VA Beth Dunn VA

Brian Craddock TN Lynda Dean Duru VA Cindy Duplissey VA

Susan Creager FL Janelle Deardurff UT Cathy Durante FL

Pat Cregar VA Madeline Dee NM Jennifer Durniak VA

Donna Criner IN Janet Demeter CA Noelea D'Antonio NJ

Marisa Cromey SC Megan DeNicola VA Lori Earl MA

Alissa Cronin FL Meghan Denny SC Heather Eck AZ

Dean Crowe GA Lindsey Deshazer MT Rebecca Eck OH

Chelsey Crowne CA Jennifer Diaz FL Emma Edwards NJ

Laura Cubarney VA Ann DiCicco VA Ellen Eggenberger MA

Kathy Cundiff IL Linda Dim IL Debra Eggleston VA

Jeanine D'Antonio NJ Sheldon Dim IL Kendra Eigenhuis GA

Andrea Dahlberg CA Candi DiMarzio VA Tamara Ekis PA

George Dahlman DC Lynn Divers VA Kristin Elder MO

Jen Daino NJ Sarah Dlabal KS Jean Marie Episcopia NJ

Ann DAlessandro NY Amanda Dobrzenski NY Julie Erickson IL

Kim Daly IL Ammy Doeden VA Tawnya Ertel CT

Riley Damiano NY Amanda Dolinsky CT Jennifer Estremera CA

Stacey Danielson VA Vincent Donofrio NJ Ann Ewbank MT

Amanda Danna VA Maria Donofrio NJ Jenna Fabbrini AZ

Wendy Fachon RI Kerry Galarza IL Chrissy Gomez TX

Courtney Fahn IL Cristy Gallagher VA Brenda Goodman VA

Shannon Fairbanks VA Ricardo Garcia MA Fiona Goodwin MD

Heather Farrell NY D Gargiulo FL Ellen Gossage IL

Josh Faulk OH Christine Garritano NY Sundeep Goswami VA

Ann Marie Feldman PA Kim Gary FL Christen Gray FL

Kelly Fenzel FL Amanda Gauldin VA Jura Greeley MA

Sharon Ferraro VA Jeri Geary TX Susan Green NJ

Joe Ferullo MI Cristib Geimer IL Lexi Grillo NJ

Patti Ferullo MI Riley Gelacak VA Ginny Grivas VA

Lori Fields OH Mike Gelacak VA Sarah Gruettner IL

Melissa Firmes NY Joyce Gelacak VA Shannon Grunwell MD

Donna Firtier VA Meredith Gelacak NY Kristen Gryglas IL

Karissa Fischer NY Michael Gelacak VA Melissa Guarino PA

Kezia Fitzgerald MA

Lacee Gengenbacher MT

Kait Gureno IL

Caryn Franca VA Cyndi Gilbert CA Cori Gustman VA

Heidi Frank OR Mike Gillette VA Amanda Haddock KS

Tim Frank OR Kristen Gillette NJ Kyley Hagan FL

Heidi Frank WI Debra Giordano CT Cindi Hager PA

Arthur Frankel VA Nicole Giroux MD Rob Hahne VA

Stephanie Freeman VA Kerry Glynn VA Janice Halash MI

Ann Friedholm MI Lisa Goldberg VA Lindsey Hall KS

Judith Fulmer SC Ranna Golden VA Julie Hall TX

Stacy Gad FL Andrew Goldin CO Sharon Hallman VA

Becky Gadomski IL Dee Gomer NJ Kimberly Hampton OH

Julie Hansen GA	Tara Hickey VA	Amanda Huhnke IN
Emily Hardy IN	Mike Hickey VA	Sydney Hurley AL
Abby Harrison VA	Michael Hickey VA	Lizette Hurtado AZ
Kelly Hart NC	Emma Hill WY	Kalli Hyde MT
Jean Hartley CA	Madison Hill ID	Alma Ibanez IN
Rebecca Hastings WA	Erin Himes PA	Jennifer Ieraci NY
Amber Hathaway CA	Kira Hnidey TX	Megan Imbert TX
Lauren Hating VA	Heather Hobbs OR	Margarita Iosiphakis NJ
Lauren Hating VA	Tracy Hobiena VA	Crystina Irwin OR
Heather Hayes NC	Jackie Hodge CO	Lauren Isbell AR
Michela Haywood HI	Samantha Hoey IL	Dylan Ivy LA
Veronica Headings KS	Deliece Hofen KS	Kaylan Ivy LA
LeAnna Headley VA	Ruth Hoffman MD	Alissa Jacobs NJ
Steve Healey NJ	Dawn Holstein WV	Janeel James MD
Katie Healy VA	Jamie Homan NY	Rachel Jansheski MI
Dana Heino VA	Tamara Homolka IL	Tammy Jenkins MT
Harriet Heisler FL	Carla Hood WA	Lauren Jennings UT
Jamie Heisler FL	Sharon Hood WA	Tiffany Jensen IL
Jared Henderson UT	Ella Horan UT	Bridget Johnson MT
Stacy Hendron IL	Aaron Horn IA	Karen Johnson MT
Shannon Hensler MT	Michele Horn TX	Hayley Johnson NC
Mariana Hernandez GA	Annie Horner GA	Lindsay Johnston PA
Marlene Herschander FL	Robyn Howard-Anderson CA	Sheri Jones IA
Tanja Hess CO Jessica Hester TX		Kelli Jones OR
	Jacqueline Hubbard CT	Kaitlyn Jones NJ
	Kimmy Huggins VA	

Teresa Jones OH Lynda Key AZ Ashleigh Kussman OH

Courtney Joy CT Liz Keyser VA Emily LaBelle SC

Michael Judkins WI Angela Killinger VA Brandon Lambert VA

Nicole Kabel Ny Ellie Rose Killinger VA Barbara Landau CT

Sarah Kaczor VA Donna King UT Kathy Landmesser VA

Jennifer Kaiz IL Joy Kirby LA Kelly Lang VA

Raleigh Kalbfleisch IL Kristena Kitchen MD Jennifer Langlois VA

Emily Kallos GA Debbi Kitin VA ilona lantos VA

Sara Kaltunas MI Tracy Klainer NC Ilona Lantos VA

Adam Katkhouda VA Lili Klainer NC Christine LaPuma IL

Lauren Katz VA Peter Klainer NC Emma Larouche MA

Linda Katz VA Julie Kluth IL Susan Larrick IL

Michael Katz ME Caryn Knapp MD Baylie LeBlanc MS

Maureen Kaufman IL Jane Knight KS Lisa Lebowitz NJ

Gregg Kaufman CA Ann Knox VA Carrie Leece IA

Judy Keiper SC Donna Knutson VA Neona Leloo VA

Sarah Keller TX Mandy Koelzer MT ReLeah Lent GA

Shawn Keller TX Rena Koenig NY Jon Leopold MI

Sheila Kelly LA Jeff Konal MI Annette Leslie TX

Patricia Kelly MT Lesley Konigsburg VA Christine LeTourneau VA

Jayne Kepsel UT Candace Konrad CT Devra Lewin MN

Abby Kerber MN Chris Kostik MN Candace Lezak IL

Heather Kern VA Claudia Koziner FL Bill Liedy NC

Maurice Kessler VA Sunita Krishna PA William J. Liedy FL

Lynn Kessler VA Susan Kriz IL Haley Lightfoot IL

Jena Lilly NJ	Pam Maroulis VA	Kate McGuire NJ
Silvia Linarez IL	Angela Marra NJ	Matt McHugh PA
Camille Lindsay MT	Emily Marra IL	John McKay NV
Janice Lindsay-Kruzich	Lisa Marsh VA	Amanda Mclawhorn NC
WY	Joshua Martensen KS	Cathy McLernon VA
Shea Line ID	Elvira Martinez IN	Sarah Mcnamara IL
Kathy Liu CA	Kimberley Martini Young	Jerilynn McSorley VA
Lucy Lloyd UT	WA	Andrea McSorley VA
Camille Loccisano NY	Sonia Martins NJ Amy Meino	Amy Meinch NC
Vicki Lodden MI	Cyndi Massie WV	Kate Melzer IL
Barbara Lonergan IL	Mary Ann Massolio FL	Monti Mercer VA
Lesley Lopez WV	Colleen Mastrandea VA	Amanda Methven MS
Amy Lourenco VA	Jean Matsuk NJ	Douglas Mewis WY
Aimee Love VA	Sue Matthews NY	Sharon Meyers VA
Donna Lucchese NJ	Anne Maurer IL	Kelly Meza CA
Karen Lucht SC	Alexandra Maurer NJ	Amy Michetti NY
Andrea Lundy FL	Tracy Mawyer VA	Carol Migliore NJ
Maya Luria AZ	Vicki Maynard OH	Lisa Millar VA
Monique Maher CA	Brian Maynard OH	Bonnie Millender MA
Jackie Maloney NC	Cindy Maynard VA	Mark Miller VA
Alison Maoli NJ	Shannon McArthur OR	
Lee Marchiano CA	Michael McCown TX	Sara Beverly Miller FL
Anthony Marcinak NY	Kimberly McCullen MA	Aileen Miller VA
Ellyn Margulies IL	Joe McDonough DE	Paul Miller CO  Janet Miller Eveland PA  Tom Mitchell VA
Irina Mariano-Brown, LCSW NJ	Emily McFadden WI	
	Linda McGregor KY	

Mary Mitchell MI Suzie Navarro CA Karina Ortiz AR

Dustina Mitchell TX Joann Nawrocki NJ Tonia Osburn CA

Olivia Mollo NJ Kirstin Neal Wy Bethany Outen VA

Katie Moore OR Deborah Neff FL Amy Owen VA

Olivia Moran MN Michele Neiman VA Rebecca Owens VA

Deborah Morbeto VA Molly Nemelka MT Laura Owens MO

Lindsay Morillo VA Tina NeSmith TN Jerry O'Hara VA

Jill Morin CO Surya Neupane PA Shannon O'Neill PA

Ana Morrad VA Rita Neupane VA Steve Paine VT

Amanda Morris CT Shriya Neupane VA Eshini Panditharatna MA

D Morrison MA Sunshine Newmeyer PA Amy Pankratz SD

Jenny Mosier MD Leigh Newport VA Roe Paradiso FL

Fran Moss IL Ana Nichols IL Liza Passarelli IL

Michelle Mott VA Danielle Nicholson MI Kate Passow VA

Beth Mowery Dunn VA Onyinye Nnenji NJ Gregg Pauletti CT

Kathy Mueller VA Lori Nordsven NM Darlene Pearson LA

Jenny Mulks CA Mandy North VA Muffin Pellegrino MA

Susan Mura IL Esperanza Nunez TX Jennifer Pepper MN

Carmen Murray CA Katie Oja NY Colleen Perez NJ

Laura Muñoz NJ Maureen Olsen NJ Sandra Perkins AZ

Mark Myers GA Amy Olson IL Ellen Petko VA

Gwen Mysiak NY Kristina Olson PA Cheryl Pettit NJ

Kim Nacyk IL Marci Orchard UT Brandi Phillips OK

Erin Nahumyk IL Diana Orjuela IL Brenda Pickering IN

Sharon Nalls VA Wilnelia Ortega PA Dayna Pierzchala IL

Lynn Pintavalle FL	Kay Rawlins FL	Katie Ross PA
Laura Pishkur IL	Renee Ray IL	Anita Roussell CA
Tracey Pitcock WV	Wendy Reece CO	Breanne Rowand AZ
Stephanie Place VA	Christine Remy VA	Angela Ruckman OH
Lisa Poczatek IL	Danielle Renken VA	Sandy Rupp VA
Pat Polhemus CO	Amy Reynolds CA	Beth Ruscitti IL
Lynda Poole NY	Lindsay Rhoades VA	Joanne Salcido NC
Keith Poole NY	Nancy Richards IL	Victor Sanchez CO
Corina Pope VA	Nicole Ricken CA	Christina Scavone NJ
Sam Potts NJ	Alyssa Ricken SC	Andrea Schiffman VA
Nicole Poulard CT	Robert Ricken SC	Tim Schmelz MO
Taylor Powell MO	Kimberly Ricker MI	Lisa Schmidt VA
Christine Prichard TX	Virginia Rigolini NJ	Debbie Schodrof IL
Robin Prove OR	Abigail Ringel UT	Cyndi Schofield IL
Christie Pruyn IL	Shannon Ritchie KY	Carly Schrager VA
Nicole Puglisi NJ	Maureen Robbins VA	Robert Schreiber VA
Kim Purper MD	Chantill Roberts VA	Shannon Schulze NC
Greg Puryear NC	Ann-Charlotte Robinson	Julianna Sclafani ME
Melanie Pyle Coulter FL	VA	Sandy Scola SC
Cassie Quick IL	Claire Rodrigues NJ	Katie Sennhenn NV
Michael Quinlan NJ	Pamela Rodriguez CA	Cindy Sergot IL
Madison Quinn MA	Yazmin Rodriguez WV	Cindy Sergot IL
Jyothi Raghavan VA	Janette Romanelli NC	Jennifer Seven VA
Kimberly Ramsdell AZ Molly Rand IL	Amie Roos VA	Hannah Severyns IL
	Nancy Roscelli CA	Christina Shannon NJ
	Lauren Roscoe ND	

Alan Shapiro MD	Jennifer Skuches NJ	Anthony Stoddard NH
Lainie Shapiro MI	Jami Smith FL	Irene Stout VA
Hannah Shapiro VA	Kim Smith VA	Stephanie Strotbeck PA
Kelley Sharp NC	Hailey Socha IA	Steve Stuck MD
Lisa Shaw VA	Adrienne Sorensen NJ	Glenn Stuck CA
Erin Shaw VA	Erica Souter KS	Kathryn Stuck MD
Kelly Ann Shea Corrigann	Lisa Spaulding MI	Amanda Suazo VA
NY	Jess Spearrin CT	Campbell Sullivan CO
Sabrina Sheck IL	Ryan Spearrin CT	Ryan Sullivan ID
Gayle Sheck IL	Logan Speckhard VA	Melany Summers VA
Robert Sheck IL	Lisa Spedale IL	Susan Summers TX
Shannon Sheffield TN	Carrie Staknaker VA	Angie Suther KS
Dena Sherwood NJ	David Stalnaker VA	Alexis Swatt VA
William Sherwood NJ	Danielle Stanchi FL	Cassandra Sweet Ct
Sydney Sherwood NJ	Whitney Starr AK	Karni Syed CA
Michelle Shoemaker IL	•	•
Pamela Shrauger MT	Kelly Steffee FL	Laura Syme CO
Debbie Shull MO	David Stein MD	Wendy Symon CA
Rachel Siegman CA	Hazel Stein FL	Ulrike Szalay VA
Dinine Signorello NY	Anne Stein IL	Kristie Szejner IL
-	Dana Steinecker IL	Adela Taboada VA
Daniela Silva NJ	Tammy Steintl MT	Rachael Taillie AZ
Heidi Silvestri MD	Kai Sternstein IL	Susan Talbott VA
Brenda Sims VA	Betsy Stevons VA	Kim Tapper VA
Bob Skiffington NA	Scott Stewart VA	Joel Tarantal AZ
Pam Skinner GA		
Christopher Skorpion AZ	Lynne Stiefler NY	Gianna Taranto NJ

Joelle Taranto NJ	Gina Tufano VA	Mary Vissichelli NY
Tonilynn Taranto NJ	Regan Turner MD	Jeanne Vivona NY
Anthony Taranto NJ	Mel Turner MD	Carla Volpe NJ
Linda Taranto NJ	Melissa Turner MD	Janie Voorhis OK
Anthony Taranto NJ	Erika Tursi NJ	Serena Wade VA
Rosemary Taranto NY	Gerry Tye NSW	Hillary Waldeisen MT
BethAnn Telford PA	Peggy Tyree VA	Patty Walker PA
Amy Terrell MS	Ava Uditsky IL	Kendall Wallace WA
Stacie Terry VA	Samantha Uditsky IL	Alix Walmsley CT
Sandra Therrien MO	Barbara Uditsky IL	Ken Walsh VA
Alicia Thomasson VA	Ana Ughetti CT	Brenda Walsh SC
Christy Thrailkill MD	Courtnie Umland MT	Kathleen Walters NY
Beverley Tidwell AZ	Sandra Valle NY	Judy Walworth MI
Ashley Timmons AZ	Jordan Van Curen OH	La Tisha Wammack ID
Timothy Toler TX	Mimi Van Houten FL	Barbara Wamsley MD
Amanda Tolman IL	Jennifer Van Weezendonk	Lisa Ward KS
Evita Tomblin KY	VA	Elaina Ward VA
Dana Toohey KS	Robin Vander Voort VA	Stephanie Wargin IL
Isabel Torres TX	Silvia Vanni FL	Christina Wascher FL
Gail Toth VA	Edwin Veazey VA	Madison Watson PA
Megan Tracy IL	Linda Venezia NJ	MaryBeth Weber NC
Vicki Trajcevski IL	Andrea Verdone Gorsegner NJ	Lauren Weber MI
Zac Triumph IN	Elizabeth Vermette VA	Vanya Weglarz IL
Jackie Truzzolino NJ	Emily Vigness MT	Jennifer Weidner IL
Kelly Tucker MS	Brandi Visser MT	Matthew Weidner IL

Melissa Weinstock VA Laura Wise IL

Randy Weiss NJ Emma Witham VA

Jill Weiss VA Lisa Wood ID

Tina Welliver ME Marcia Woodward IL

Jessica Welsh VA Amber Wright UT

Robert Whan FL Kelly Wymer WV

Janessa Whatcott UT Alexandra Wymer WV

DebiJo Wheatley VA Jaymi Yamoah FL

Lynn Whipple VA Jaymi Yamoah FL

Nancy Whipple MA Elaine Yeager AZ

Lauren White VA Jaclyn York FL

Samantha White IL Alexi Zacarias NJ

Jennifer White MT Patricia Zambardi NJ

Margaret Whitt VA Raven Zeigler IL

Melissa Wiggins FL Sarah Zematis IL

Shea Wilch VA Beth Zemcik VA

Jeremy Wilch VA Jillian Zielinski FL

Maddy Wilkens IL Kathy Zillman-Ogden AZ

Angela Willis VA Emily Zimmerman PA

Claire Wilson ID Coby Zobell UT

Carol Wilson OK Barbara Zobian NY

Kelly Wing VA Susie Zuckerman FL

Carol Winnefeld IN Michele Zuckerman VA

Scott Winner IL

Geralyn Winters VA

### Appendix 5 Letter of Support from Alliance for Childhood Cancer for the Gabriella Kids First Research Act 2.0



June 22, 2020

Representative Jennifer Wexton U.S. House of Representatives 1217 Longworth House Office Building Washington, DC 20515

Representative Peter Welch U.S. House of Representatives 2187 Rayburn House Office Building Washington, DC 20515 Representative Tom Cole U.S. House of Representatives 2207 Rayburn House Office Building Washington, DC 20515

Representative Gus Bilirakis U.S. House of Representatives 2227 Rayburn House Office Building Washington, DC 20515

Dear Representative Wexton, Representative Cole, Representative Welch, and Representative Bilirakis:

The undersigned childhood cancer organizations are members of the Alliance for Childhood Cancer, consisting of patient advocacy groups, healthcare professionals and scientific organizations, representing millions of Americans who care deeply about childhood cancer. We are writing to offer our endorsement of H.R. 6556, the Gabriella Miller Kids First Research Act 2.0. Thank you for your leadership in the fight against childhood cancer.

More children are lost to cancer in the U.S. than any other disease. Before they turn 20, about 1 in 285 children in the U.S. will have cancer; about 16,000 children receive a cancer diagnosis each year. While recent decades have seen dozens of new cancer therapies, there are very few cancer treatments that are specifically indicated for pediatric cancer. Further, survivors of childhood cancer often suffer long term health consequences due to the side effects of the treatment regimens available today. Despite the significant unmet medical need, the research in pediatric cancer has not met the medical needs of children and families.

The Gabriella Miller Kids First Act 2.0 will build upon the successes of the original Gabriella Miller Kids First Act, enacted in 2014, which has invested \$75 million in childhood cancer research and is expected to fund another \$50 million before it sunsets in 2023. Further, the Act will expand the Kids First Program, which supports collaborative research to uncover the genetic etiology of childhood cancer and structural birth defects. The Kids First Program holds promise to facilitate more refined diagnostic capabilities and ultimately more targeted therapies or interventions.

The Gabriella Miller Kids First Act 2.0 authorizes continued resources to improve treatment of childhood cancer by advancing the research that brings us closer to finding a cure. Thank you for your leadership on behalf of children with cancer. We look forward to working with you enact The Gabriella Miller Kids First Research Act 2.0. Should you have any questions or need



additional information, please contact Sarah Milberg, Co-Chair of the Alliance for Childhood Cancer, at <a href="mailto:smilberg@allianceforchildhoodcancer.org">smilberg@allianceforchildhoodcancer.org</a>.

Sincerely,

#### The Alliance for Childhood Cancer

American Cancer Society Cancer Action Network

American Childhood Cancer Organization

American Society of Pediatric Hematology/Oncology

The Andrew McDonough B+ Foundation

Association for Clinical Oncology

Association of Pediatric Hematology/Oncology Nurses

Association of Pediatric Oncology Social Workers

Children's Brain Tumor Foundation

Children's Cancer Cause

Children's Oncology Group

Leukemia & Lymphoma Society

Mattie Miracle Cancer Foundation

National Brain Tumor Society

Rally Foundation for Childhood Cancer Research

Sarcoma Foundation of America

St. Baldrick's Foundation