



2019 PROGRESS REPORT

The Bridge to a Cure Foundation is an advocate for modernizing our country's approach to Childhood cancer research, with a priority on building a childhood cancer database.

STRATEGY

To manage the problem as a process improvement opportunity, whose solution depends on a holistic approach that engages participation from the medical community, pharmaceutical and technology companies, investment and investor communities, nonprofits/foundations and donors, and various government agencies.

OBJECTIVES

As advocates for modernizing our country's approach to childhood cancer research, our short-term focus and objectives are to:

- ♥ Identify the issues surrounding childhood cancer research and the reasons why.
- ♥ Secure support for or improvements to the remedies we have proposed.
- ♥ Advance the building of a robust and dynamic national childhood cancer database, the foundation's number one remedy priority.
- ♥ Implement a program to build awareness to each of the above.

PROGRESS SUMMARY

Via a series of articles, presentations and social media releases we have:

- ♥ Gained agreement amongst a wide range of cancer stakeholders and practitioners as to:
 - ♥ The unacceptable state of childhood cancer research, and
 - ♥ The reasons research advancements have been disappointing.
- ♥ Received broad acknowledgement to the remedies we proposed.
- ♥ Our proposal to the director of The National Cancer Institute (NCI) has led to the government funding of a national children's cancer database – Children's Cancer Data Initiative (CCDI).
- ♥ Launched a broad-reaching advocacy program to build awareness of the issues and remedies.

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DETAILS

THE UNACCEPTABLE STATE OF CHILDHOOD CANCER RESEARCH

Childhood cancer research and oncology have attracted some of the best minds and institutions. They are dedicated, brilliant and caring. They want to make a difference. They also want to dramatically improve upon the current state of childhood cancer research.

- ♡ Since 1980, fewer than 10 drugs have been developed for use in children with cancer.
- ♡ Of the \$3.65 trillion we spend on healthcare annually, only 2/10th of 1%, or \$7.3 billion, is spent on childhood cancer research.
- ♡ Cancer remains the number one cause of death by disease among children.
- ♡ Survival is defined by living a meager five years after treatment.
- ♡ For the child and family, the five-year span is fraught with horrific suffering, excruciating emotional strain and deteriorating financial stability.
- ♡ There has been no change to the survival rate for children with brain and other nervous system cancers for the past 20 years.
- ♡ More than 95% of childhood cancer survivors will have a significant health-related issue by the time they are 45 years of age. These health-related issues are side-effects of either cancer or more commonly, the result of its treatment.

REASONS ADVANCEMENTS HAVE BEEN DISAPPOINTING

There are three overarching reasons why breakthrough treatments and cures have been rare.

1. Research Barriers

- ♡ Insufficient data – Valuable data is constrained to the researcher’s or institution’s own research findings and patient records, and published materials. Research data and experimentation are the crucial components to discovery. Data is what’s crucial to research. Surprisingly, our nation does not have a robust database for each childhood disease and disorder.
- ♡ Disease complexity – The constant evolving nature of cancer results in massive amounts of data that exceeds the researcher’s ability to digest and analyze.
- ♡ Clinical trials – The mandated clinical trial protocol was written for adults, not children. Further, 70% of the treatments approved for trial never go to trial. Not enough patients sign up. Funding is often not available. The clinical trial process is slow, expensive and is not always practical in a life and death situation. To learn more, read our [January 23, 2020 blog – The Childhood Cancer Clinical Trial Debacle \(Part I\)](#).

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- ♥ Inadequate knowledge sharing – While there is more collaboration than before, it needs to go further. The limiting factors are culture, government regulations, and reward/recognition systems. Breakthroughs in childhood research would escalate by capturing the synergies derived by greater transparency and collaboration. To learn more, read our [March 15, 2018 blog – Seize the Potential of Collaborative Data to Help Kids.](#)
- ♥ Dearth of alternative medicine – Alternative treatments are excluded from the mainstream, despite favorable anecdotal evidence. Many of these remedies deserve the same consideration as the drugs recommended by the pharmaceutical industry.
- ♥ Government delays – The FDA approval process is unnecessarily slow.

2. Scarcity of Funds

- ♥ Our country's healthcare investment shortchanges childhood cancer research – Of the \$3.65 trillion we spend on total healthcare, only 5% is spent on research and an appalling 2/10th's of 1% on childhood cancer research.
- ♥ Pharmaceutical companies won't invest – The market is too small to justify the investment as it would not generate the financial return investors demand.
- ♥ Ineffective use of donor contributions – Too often, less than 20% of donations go to research. The little that does has not been successful. Charities are also notorious for using the donated money inefficiently, with 80% of the funds going to fundraising or administration. Bottom line, too many are not performing.
- ♥ Investment stimulation initiative didn't work – Federal laws meant to encourage drug companies to invest in pediatric clinical trials have not been effective.
- ♥ Allocation of taxpayer revenue directed to adults, not children – Only 4% of the National Cancer Institute's budget is invested in childhood cancer research.

3. Insufficient Level of Participation and Collaboration

- ♥ Research burden not shared – The pharmaceutical, investment and nonprofit communities are not fully immersed strategic partners.
- ♥ Constraining regulations – This includes privacy protection requirements and limitations of current antitrust rules.
- ♥ Culture, norms, habits and attitudes.
- ♥ Protective agendas by foundations and nonprofits – There are more than 1.5 million foundations and nonprofits in the United States – an average of 40 for every US zip code – including countless charities devoted to pediatric cancer and numerous other childhood diseases. Often, they lack the kind of governance that's standard in the corporate world and are frequently managed by people who lack management and

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business experience. These organizations are myopic in their approach and protective of their agenda.

REMEDIES PROPOSED BY THE BRIDGE TO A CURE FOUNDATION

1. Research Barriers

To improve upon the current state of childhood cancer, the research and medical community will need to prevail over the barriers that have hampered their ability to deliver the breakthroughs they had hoped for. Through a series of presentations and media releases we have earned recognition that our remedies make sense.

- ♥ Insufficient data – Build a robust national childhood cancer database that would provide researchers and others access to the 100s of millions of pages of information about the disease, all medical files, the science for every treatment, drug and alternative medicine and more. To learn more, read our [September 24, 2019 blog – Dying in the Dark](#) and our [April 15, 2019 blog – Stop Pediatric Cancer Like We do Terrorists](#).
- ♥ Disease complexity – Capitalize on the proven capability of artificial intelligence. Research institutions have been slow to embrace this technology, trusting more in the mind of the researcher alone. Once a robust national cancer database is developed, we need to provide the methodologies and tools for researchers to extract meaningful findings. There are computers that can read and review 100s of millions of scientific pages in seconds. Algorithms can be written to analyze, discover and predict from the data a robust national cancer database would provide. To learn more, read our [February 15, 2018 blog – Putting the Pieces Together for the Fight Against Cancer](#).
- ♥ Clinical trials – Simplify, sensitize and modernize the clinical trial process by speeding up and reducing complexity. Pursue simulated research. Balance life expectancy and quality of life. Exemptions for terminal patients. To learn more, read our [January 31, 2020 blog – Solving the Clinical Trial Debacle](#) and the [July 25, 2019 blog – The National Cancer Institute Knows How to Cure Pediatric Cancer](#).
- ♥ Inadequate knowledge sharing – Align research initiatives and implement reward and recognitions incentives that encourage collaboration within and across institutions. To learn more, read our [November 25, 2019 blog – Why Reward Systems are Barriers to Pediatric Research Breakthroughs & How to Fix it](#).
- ♥ Dearth of alternative treatments – Develop a methodology to evaluate/approve alternative medicines/treatments. To learn more, read our [May 29, 2018 blog – Breaking Down Barriers, Bridging to A Cure](#).
- ♥ Government delays – National Cancer Institute (NCI) and the Federal Drug Administration (FDA) should delegate responsibility for all phase I and II trials to NCI approved cancer centers. To learn more, read our [December 13, 2019 blog – Hamstringing Pediatric Cancer Research](#).

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2. Scarcity of Funds

We will need more than just a fresh approach to generate the funds required to finance childhood cancer research. We presented strong evidence to support considerations to the following proposals:

- ♥ Our country's healthcare investment shortchanges childhood cancer research – We need a national healthcare strategy that is both sensitive, pragmatic and sustainable. In our view, failing to invest in childhood research is unacceptable. A discerning review of current spending in end-of-life care vs. childhood research deserves consideration. To learn more, read our [October 8, 2019 blog – Inefficiency, Inertia, and Waste Drive Us to Spend \\$3.65 Trillion on Healthcare Annually: It's Time to Focus on Research.](#)
- ♥ Pharmaceutical companies won't invest – We are at a moment in history where the corporate mantra of maximizing shareholder value alone is insufficient. Corporations should do more to better mankind – and they should be rewarded for it. In our May 2019 blog, we introduced the Millennial Organization. It revolutionizes the criteria for valuing organizations. The blog provides detailed evidence to support that the time has come for the Millennial Corporation – the organization whose stock value reflects not only sustainable profit growth but also its contributions to improving the human condition. Now is the time for the investment community and pharmaceutical industry to redefine the matrices for valuing this industry. Investing in childhood cancer would be a good place to start. To learn more, read our [May 28, 2019 blog – The Cure to Pediatric Cancer is at Our Fingertips.](#)
- ♥ Ineffective use of donor contributions – donors should demand accountability, including where their funds are directed. We recommend that nonprofits channel their investments to efforts intended to remove the research barriers identified above, that have hindered meaningful breakthroughs. Fixing the childhood clinical trial process or funding a national data base would be a good place for them to start. To learn more, read our [July 3, 2019 blog – Donors Hold the Key to Curing Pediatric Cancer.](#)
- ♥ Investment stimulation initiatives not effective – Demand pharmaceutical companies invest in childhood cancer research. We suggest that if the government can demand that carmakers invest in seat belts, it should be able to make reasonable demands on pharmaceutical companies to invest more in childhood cancer research. To learn more, read our [December 13, 2019 blog – Hamstringing Pediatric Cancer Research.](#)
- ♥ Allocation of taxpayer revenue directed to adults, not children – Let the pharmaceutical companies focus on adults, where the investment returns are. NCI should allocate funds to where the money is not – childhood cancer research. This is another reason why we need a coordinated national strategy with representation

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from all stakeholders to prioritize the allocation of funds, which are already in short supply.

3. Insufficient Level of Participation and Collaboration

- ♥ Research burden not shared – To solve the many urgent challenges that individuals and institutions have failed to solve on their own, science must be able to harness ideas, people and resources from across disciplinary and organizational boundaries. We need to expand participation to include all sectors, with each actively involved in the development of a shared mission, strategy and plan. NCI should lead this initiative.
- ♥ Constraining regulations – Revisit antitrust and other laws and regulations that restrict collaboration. To learn more, read our December 13, 2019 blog – To learn more, read our [December 13, 2019 blog – Hamstringing Pediatric Cancer Research](#).
- ♥ Culture, norms, habits and attitudes – Develop a reward and recognition system unique to childhood cancer research; one that reinforces a culture of collaboration; one that spans from researcher to investor. To learn more, read our [November 25, 2019 blog – Why Reward Systems are Barriers to Pediatric Cancer Breakthroughs](#) and our [May 29, 2018 blog – Breaking Down Barriers, Bridging to a Cure](#).
- ♥ Protective agendas by foundations and nonprofits – Appoint an umbrella organization whose role is to identify opportunities for consolidation, collaboration and optimization of synergies as it relates to childhood cancer research.

BUILD A NATIONAL CHILDHOOD CANCER DATABASE

In September of 2017, the five process improvement areas identified by the Bridge to a Cure Foundation were presented to Dr. Ned Sharpless, the Director of the National Cancer Institute. This included the preliminary framework for a national childhood database (attachment 1). Thanks to Dr. Sharpless' leadership, the need for a childhood database gained acceptance amongst 90% of oncologists and researchers.

The childhood database acceptance was culminated with President Trump's announcement in the 2019 State of the Union that the proposed budget included \$500 million over the next ten years to fund the newly formed Childhood Cancer Data Initiative (CCDI). The first conference was held July 29-31, 2019. At this conference, the mission of CCDI was discussed. We are encouraged that it addresses three of the five process improvement areas that the Bridge to a Cure had presented to Dr. Ned Sharpless in September 2017:

- ♥ Collecting critical data (national database)
- ♥ Analyzing (artificial intelligence technology)
- ♥ Sharing data (collaboration)

IMPLEMENT A BROAD-REACHING ADVOCACY PROGRAM

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Defined the audience we need to target:

- ♥ Pediatric and Cancer Research Community
- ♥ National Cancer Institute
- ♥ Cancer Foundations and Nonprofits
- ♥ Pharmaceutical Companies and Associations
- ♥ Machine learning Tech Companies
- ♥ Investment Companies and Associations
- ♥ Parents and Grandparents
- ♥ Public

Implemented a multifaceted communication plan to reach our target audience:

- ♥ Medical Trade Journals
- ♥ Pediatric Journalists
- ♥ Bloggers
- ♥ Social Media
- ♥ Public Media – radio and print
- ♥ Power Point Presentations
- ♥

THREE YEAR PLAN

The Bridge to a Cure Foundation is making a difference. Our mission has gained broad support and recognition. But we can do more. Our momentum is strong and with the right resources we can capitalize on the advances we are making in awareness, support and level of influence. The below three-year plan captures the investment required to advance the foundations mission.

GOALS

- ♥ Monitor and influence the National Cancer Institute's (NCI's) Childhood Cancer Center Data Initiative:
 - ♥ Invitation by NCI to be an active participant, provide ongoing feedback and recommendations.
 - ♥ Expand CCDI initiative to include alternative medicines/treatments.
 - ♥ Add representation from pharmaceutical, technology, and other sectors to provide input to database framework and to identify/address technical and execution issues.
- ♥ Launch of NCI initiative to simplify, sensitize, and innovate the pediatric cancer clinical trial process.
- ♥ Gain endorsement of key influencers across the pediatric cancer community:
 - ♥ Medical
 - ♥ Foundations/nonprofits

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- ♡ Pharmaceutical
- ♡ Machine Technology
- ♡ Investment

FUNDING REQUIRED

(\$000)

EXPENSE	YEAR 1	YEAR 2	YEAR 3	TOTAL
Executive Director & Admin Asst.	56	96	96	248
Legislative Relations	32	96	96	224
Public Relations	74	96	96	266
Fundraising Campaign:	55	30	30	115
Website Develop/Maintenance	25	6	6	37
Videos	40	60	60	160
Awareness Campaign	75	90	90	255
Market Research	10	-	-	10
Social Media & Engagement	30	24	24	78
Database Building	20	12	12	44
Blogging	15	24	24	63
TOTAL	432	534	534	1,500

The above activities are nationwide. We believe that these initiatives will:

- ♡ Obtain the public support necessary to influence the funding and allocation of resources to:
 - ♡ Make meaningful progress toward completing the Childhood Cancer Data Initiative.
 - ♡ Reinvent the childhood cancer clinical trial process
 - ♡ Advance other remedies proposed by our foundation.
- ♡ Recruit Childhood Cancer key influencers to actively endorse the foundation's crusade to improve our nation's childhood cancer research approach.
- ♡ Raise the financial support necessary to fund these programs.

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In closing, I am pleased to welcome Ken Asher and Gary Tapella to our Board of Directors and Wendy Payton, executive director, and Judy Dannemiller administrative assistant to the foundation's team. Each comes with excellent credentials and a strong commitment to the Bridge to a Cure's mission. I will continue to be fully engaged.

Sincerely,

Robert Martin

President

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Attachment 1

CHILDHOOD RESEARCH DATABASE FRAMEWORK

The chart attached is a high-level representation of the framework. The category, “environment”,

TREATMENT	POINTS OF ATTACK			
	DISEASE	CAUSE	ENERGY	ENVIRONMENT
Pharma Eastern Vitamin Diet Device Etc.	Medical Files Research Anecdotal Evidence Other			

pertains to the processes and systems that have been compromised by a terminal disease such as the immune system, angiogenesis, the lymphatic system, the circulatory system, the hormone system, apoptosis and more.

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