



December 14, 2009

Dr. Loré Anne McNicol
Director, Division of Extramural Research
National Eye Institute
National Institutes of Health
Suite 1300
5635 Fishers Lane
Bethesda, MD 20892

Dear Dr. McNicol,

Thank you for the considering our proposal to establish Eyes for Iowa, a nonprofit organization dedicated to advocating, coordinating, and educating (ACE) on behalf of Iowa children with congenital eye defects (CED). Our organization will fulfill the mission of the National Eye Institute to “fight blinding eye diseases” and to “preserve sight” in children.

In the United States, 3 out of every 1,000 babies have some sort of CED, but only 15% receive updated medical treatment. Without treatment, children with CED face impaired vision or blindness, which can lead to developmental delays and lower test scores in school. Children with CED and their families need a central organization to provide information and support, but no such organization exists.

Central Iowa needs an organization to help its children with CED. Hopara Consulting will create Eyes for Iowa with your support and the support of the Central Iowa community. Using the ACE system (advocate, coordinate, educate), Eyes for Iowa will be a central resource for children with CED and their families.

In this proposal, you will find our plan for creating Eyes for Iowa, including the following sections:

- Background on CEDs and the need for the foundation
- The methodology we will use to create the foundation
- Our unique qualifications to lead this effort
- Specific benefits for the state of Iowa

Thank you again for considering our proposal. We look forward to hearing from you and the committee.

Sincerely,



HOPARA
Consulting

EYES FOR IOWA
*A Nonprofit Foundation
for Children's Eye Care*

A Proposal to the National Eye Institute

From Hopara Consulting

December 12, 2009

TABLE OF CONTENTS

Background..... 1

Vision Is Vital to Development..... 1

Development Is Vital to Educational Success 2

Eye Defects Can Be Treated 2

Eye Defects Are Not Being Treated 3

No Group to Help Children with CED 3

We Will Create Eyes for Iowa..... 4

Proposed Methodology..... 5

We Will Divide Implementation Tasks into Four Phases 5

Phase I: Establish a Stable Foundation..... 6

Phase II: Fulfill Legal Requirements 7

Phase III: Prepare Finances for Future Success 8

Phase IV: Evaluative Procedures 8

Qualifications 9

We are committed to helping Iowa families..... 9

We have implemented several successful comparable programs..... 9

The Literary and Arts Foundation of Greater Des Moines..... 9

Project Learning Tree 9

Hearts for Iowa 10

ACORN 10

Hopara Consulting is uniquely qualified to implement this program..... 10

Benefits of Establishing Eyes for Iowa..... 12

The number of children who become blind from untreated CED will be reduced.12

Children with CED are more likely to meet major milestones by age 2..... 12

Test scores of Iowa children with CED will increase..... 13

Appendix A: Children with Congenital Eye Defects, 2001–2005 15

Appendix B: Received In-Kind Donations 16



Appendix C: Map and Floor Plans of Eyes for Iowa Facilities..... 17

Appendix D: Establishing Hearts for Iowa, a Case Study 18

Appendix E: Testimonials..... 19

Appendix F: Early Donations 20



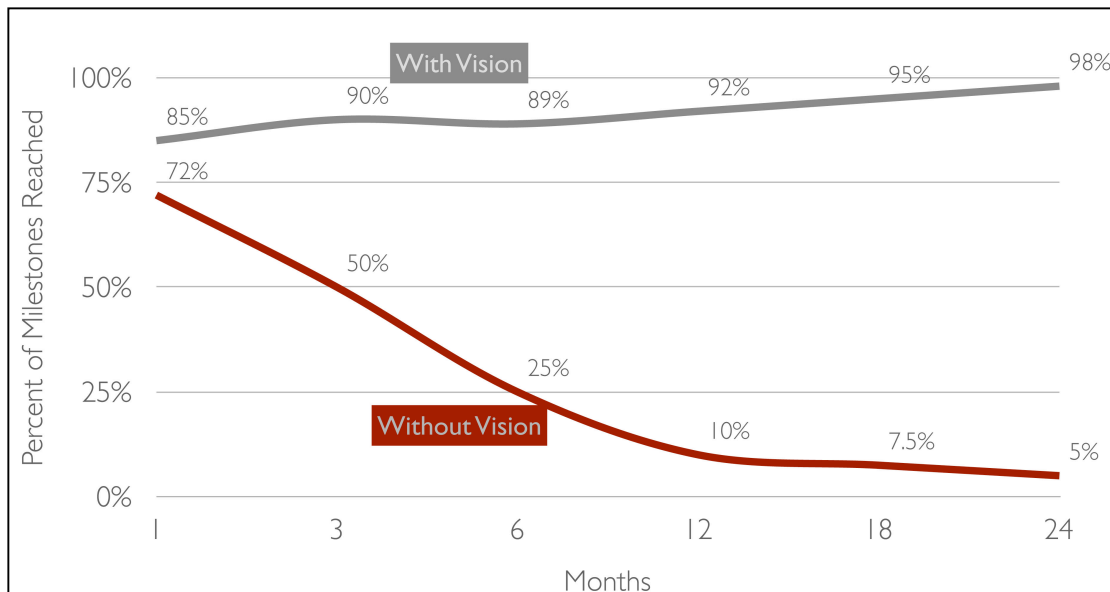
BACKGROUND

VISION IS VITAL TO DEVELOPMENT

Before a child's reaches age two, he or she should achieve several "milestones" defined by the American Medical Association: rolling over, sitting, balancing, walking, and running; and reaching, grasping, holding and playing with objects.¹ These milestones in turn affect many other areas of a child's development.

Imagine, however, a child attempting to achieve these milestones without vision. Each year, 3 out of every 1,000 children born in the United States has some sort of congenital eye defect (CED) that affects their ability to see. While these children eventually adapt to their lack of vision, they are often delayed in reaching major milestones. As shown in Figure 1, children able to see reach more than 85% of milestones in their first month and increase that percentage steadily through the first two years. Children without vision, however, meet only 72% of milestones in their first month. By the end of two years, children without vision meet only 5% of the milestones—an unacceptable number that has far-reaching effects.

Figure 1: Without vision, children struggle to achieve major milestones



¹ *Early Childhood Developmental Milestones*, American Medical Association, 1999.



DEVELOPMENT IS VITAL TO EDUCATIONAL SUCCESS

A child who misses major milestones will also have problems once he or she begins school. In our study of children with untreated CED,² we found that they scored an average of 45% lower on the Iowa Tests of Basic Skills (ITBS) through the sixth grade. While other factors affected these test scores, we found the strongest link between delayed early childhood development as a result of an untreated CED and lower test scores. In other words, untreated CEDs can cause lifelong problems.

EYE DEFECTS CAN BE TREATED

The good news is that many CEDs can be treated if caught early enough. Providing timely care increases a child's ability to see, to achieve milestones, and to be fully prepared for educational success. To be most successful, however, doctors must begin treatments within the first two months of a child's life. After that point, the child's brain begins to ignore signals from the affected eyes, making it more difficult for doctors to restore vision.

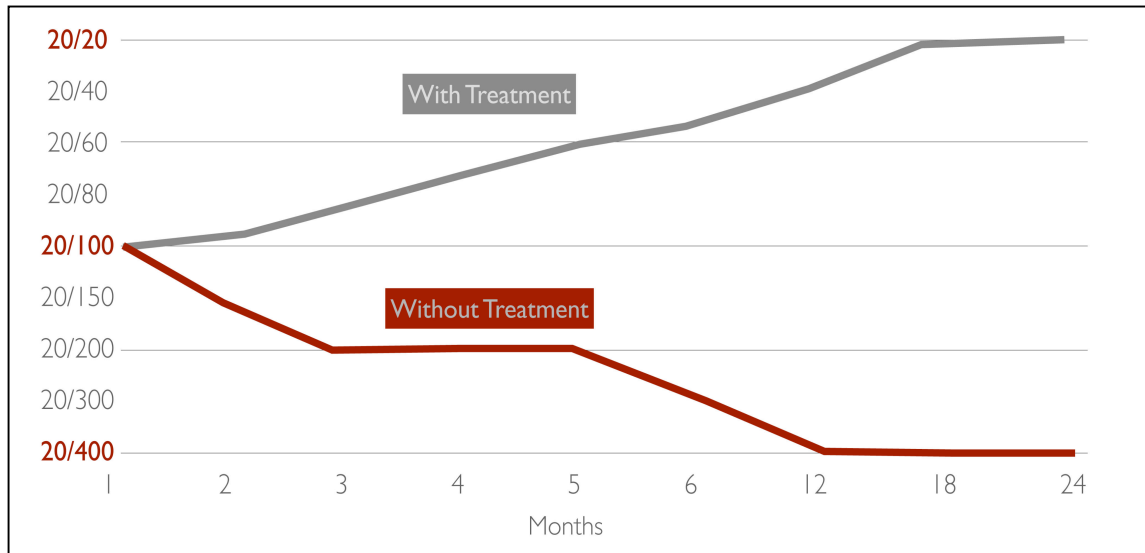
As shown in Figure 2, children with CED who receive proper treatment can progress to normal adult vision within two years. On the other hand, children who do not receive treatment are usually completely blind in one or both eyes within two years.³

² As part of our preliminary work on this project, we tracked the test results of children with CED for five years. For a full report on our study, see Appendix A: Children with Congenital Eye Defects, 2001–2005.

³ See Charles McDaniels, "Recovering Vision in Early Childhood," *Ophthalmology Quarterly* 1 (2007): 56–78. Although vision is more difficult to recover after the first two months, eye surgeries and other treatments for infants have only been developed in the last two decades. McDaniels shows that doctors need to be better educated in modern treatments in order to treat children earlier and achieve greater success.



Figure 2: Timely care is crucial to recovering vision



EYE DEFECTS ARE NOT BEING TREATED

Unfortunately, many children with CEDs are not treated. In the United States, 3 out of every 1,000 children born are affected by some kind of CED. That equates to roughly 200 of the children born in Central Iowa each year. In establishing the need for this foundation, our background research found that nearly 85% of Iowa’s children with CED do not receive proper medical care. The primary reasons for this lack of care include (1) the treatments are expensive; (2) the treatments are only available near major medical centers; and most of all, (3) families, doctors, and educators are not aware of the latest treatment options.⁴

NO GROUP TO HELP CHILDREN WITH CED

Most childhood conditions have a national foundation to help ensure families and doctors are aware of treatments and other issues. However, there is no central organization for children with CED. Therefore, children, families, and doctors have no place to turn for information or support for CEDs. According to our preliminary study, no organization exists because of the following reasons:

1. **CEDs are rare.** In relationship to other childhood conditions, CEDs are very rare.
2. **Treatments for CED are relatively new.** Until the last two decades, many forms of CED were considered untreatable. Major advancements in vision technology allow children to be treated, but only 65% of medical

⁴ See Appendix A.



professionals are aware of the new procedures, and only 31% are fully trained to conduct the treatments.⁵

3. ***CEDs lack publicity.*** Other eye conditions, such as glaucoma, and other childhood conditions, such as cleft palate and Down Syndrome, are more publicized in the media. This lack of media attention for CEDs has affected the slow development of a central group.

WE WILL CREATE EYES FOR IOWA

The best way to help children with CED in Iowa is to create a unifying organization. In connection with the goals of the National Eye Institute to fight blinding eye disease and preserve sight, we will create Eyes for Iowa, an organization that will use the ACE system (advocate, coordinate, and educate) to help children with CED in Central Iowa.

As a result of our study, we have initiated plans for Eyes for Iowa. Through the generosity of the Charitable Development Organization of Des Moines, we have acquired a building that will house the foundation's offices.⁶ The building's location will provide easy access to doctors and state government offices. Its size will accommodate our initial professional staff as well as providing room to grow as the organization expands.⁷

We have designed a plan to create the new foundation. When created, Eyes for Iowa will provide the following benefits to children with CED in Central Iowa:

1. There will be an organization to advocate, coordinate, and educate for Iowa children with CEDs.
2. By 2012, the number of children who go blind from untreated CEDs will be reduced by 50%.
3. Children with CEDs will meet 85% of major milestones by age 2.
4. Test scores of children with CED will rise by 30% in ten years.

⁵ McDaniels, 72-74.

⁶ See Appendix B: In-Kind Donations Already Received.

⁷ See Appendix C: Map and Floor Plans of Eyes for Iowa Facilities.



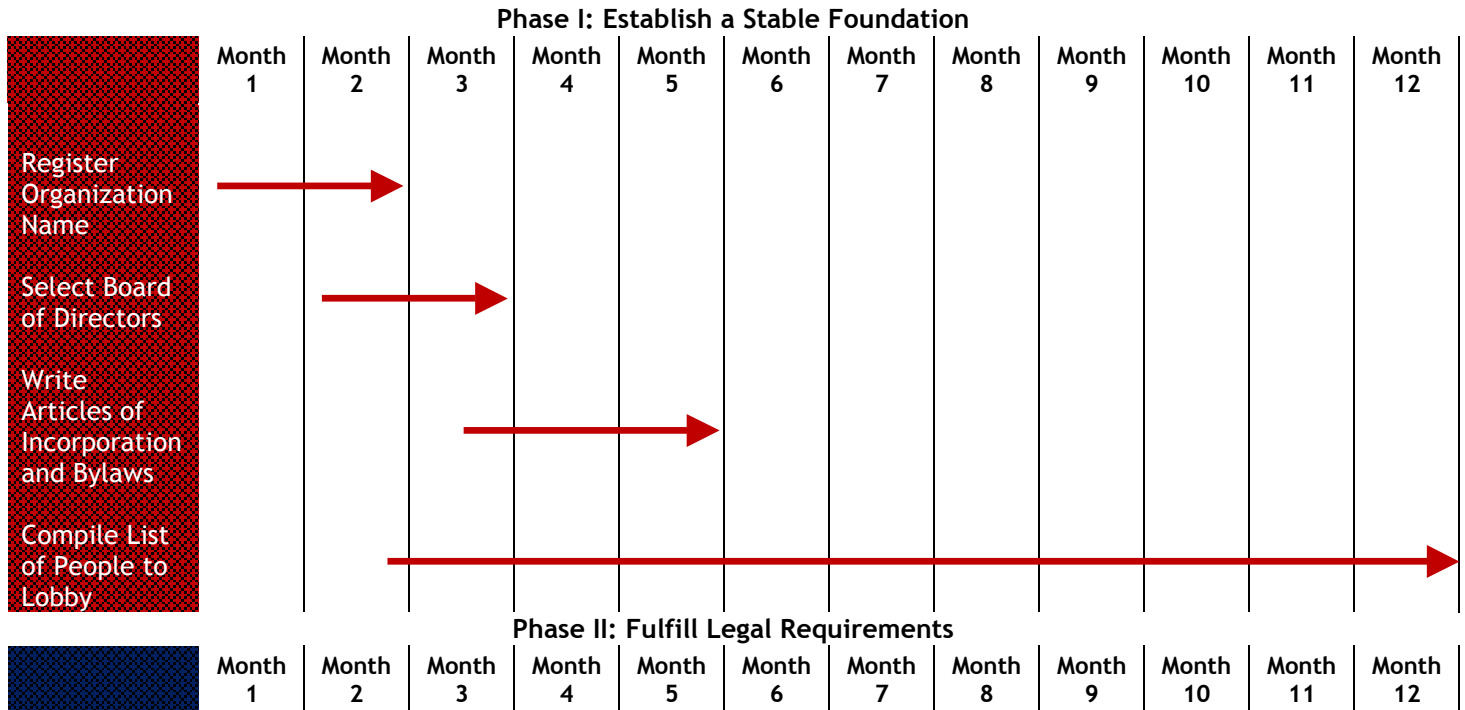
PROPOSED METHODOLOGY

To create a central foundation for Iowa children with a CED, we have developed a methodology based on our lessons learned from our previous projects. These lessons learned include stability, sustainability, and expandability.

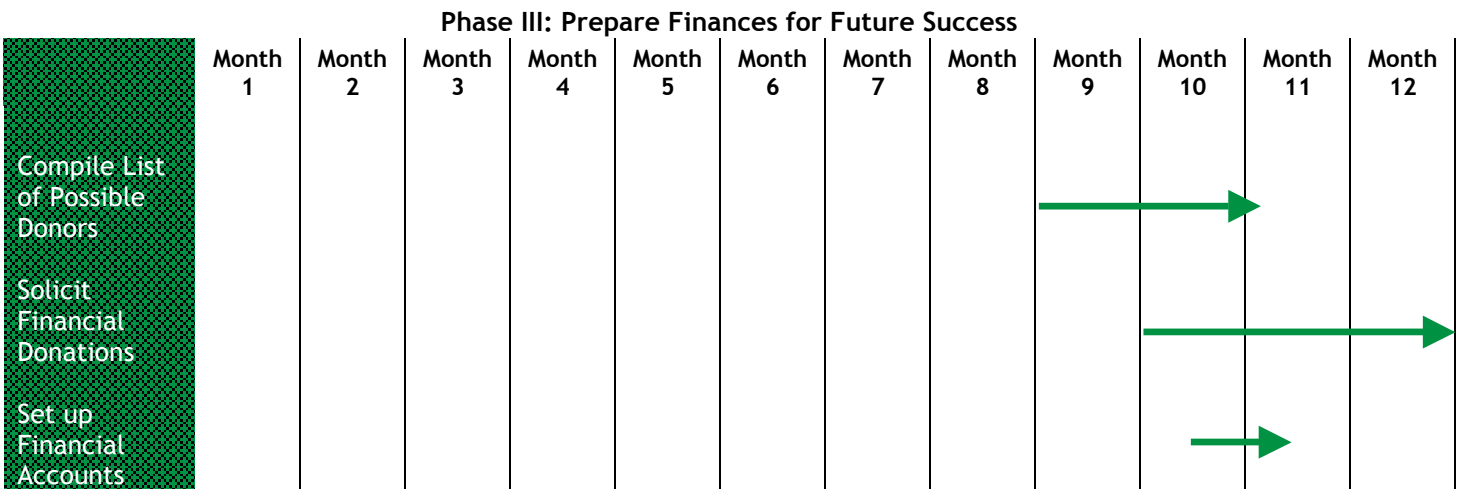
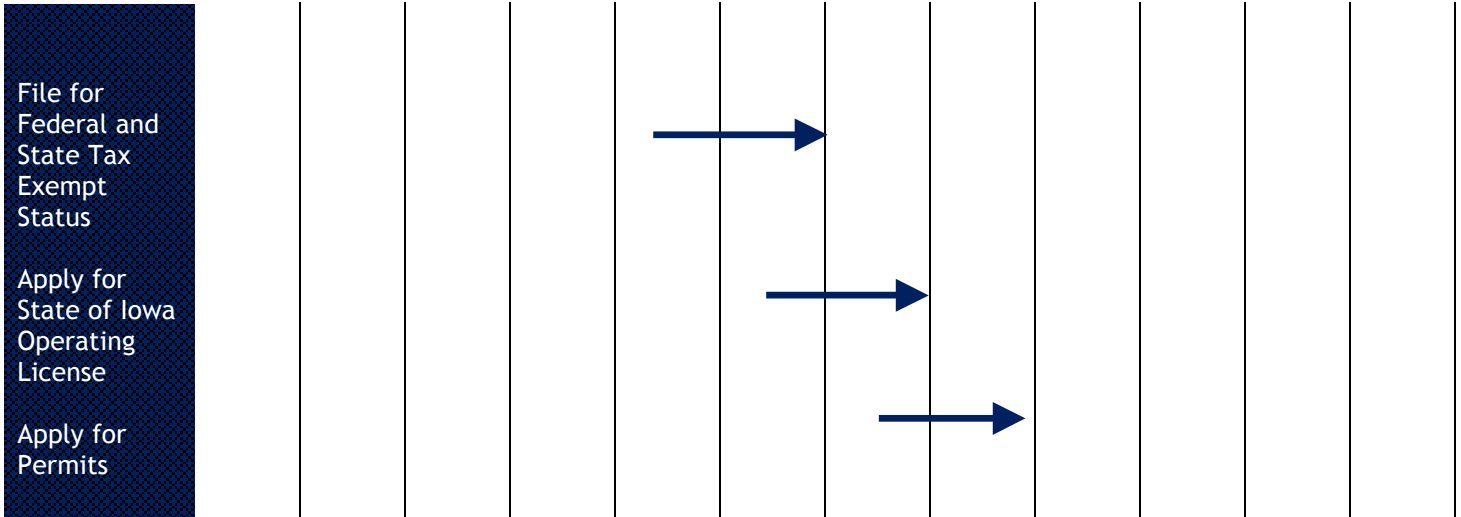
From establishing other successful foundations,⁸ we know the importance of forming a sustainable foundation by creating and maintaining an independent financial source. Establishing a streamlined methodology will enhance the expandability of Eyes for Iowa. Finally, choosing board members who will act to prevent “Founder’s Syndrome”—where the foundation acts according to the founders’ personalities instead of the foundation’s mission—is crucial for the stability of Eyes for Iowa.

WE WILL DIVIDE IMPLEMENTATION TASKS INTO FOUR PHASES

We have designed a straightforward methodology with four specific phases. The following Gantt chart provides an outline of these phases which we explain in greater detail below.



⁸ See Appendix D: Establishing Hearts for Iowa, a Case Study; and Appendix E: Testimonials.



Phase I: Establish a Stable Foundation

In this phase, we will officially establish our foundation by forming a Board of Directors and filing the proper forms with local, state, and federal government to register Eyes for Iowa. This phase will establish our foundation as a government-recognized non-profit with a board ready to provide guidance to its projects. Initially, our tasks will include

- Registering the name “Eyes for Iowa”
- Drafting and finalizing our foundation’s mission statement
- Forming a legally recognized Board of Directors

To form a legally recognized Board, we will first identify guidelines for Board members, including the number of members and their roles. We will then put in place a process that recruits and selects applicants from an application process



for interviews, chooses Board members, and leads an orientation for new Board members.

The Board of Directors, once established, will then undertake the following tasks during this first phase:

- Retaining legal counsel
- Writing Bylaws and Articles of Incorporation
- Completing and submitting required progress reports to the National Eye Institute
- Submitting Articles of Incorporation and other reports to the State of Iowa
- Compiling a list of people to lobby

Deliverables

During this phase, we will complete several deliverables which will provide guidance for Eyes for Iowa as it carries out its mission to help Iowa's children. Additionally, these deliverables could also be used to guide similar foundations, making our plan replicable. These deliverables include

- A clear mission statement to guide the foundation's work
- Specific requirements for specific seats on the Board of Directors
- An established process for selecting Board members
- An established Board of Directors
- Articles of Incorporation and Bylaws to govern the structure of the foundation

Phase II: Fulfill Legal Requirements

In this phase, we will take care of the legal precautions required to found a non-profit foundation. Where the first phase gave the foundation official recognition and an established system of leadership, this phase will fulfill the legal requirements.

To complete the legal requirements, we will

- Hire financial counsel
- Receive Board approval for tax-exempt status
- File for federal, state and city tax-exempt status with Internal Revenue Service (IRS)
- Consult legal counsel before applying for necessary licenses and permits
- Submit request for solicitation license to local city offices
- Submit request for a mail permit to local post office

Deliverables

During this phase, we will complete several deliverables, which are important to our status as a non-profit foundation. These deliverables include



- Tax exempt status at the federal, state and city levels
- Solicitation license
- Mail permit

Phase III: Prepare Finances for Future Success

In this phase, we will establish a process of continuous financial support for Eyes for Iowa. This support process will include finding and soliciting potential donors.⁹

In order to acquire the needed funds, we will

- Identify groups with common interests and obtain mailing lists to lobby
- Determine initial financial goals
- Start a fundraising campaign
- Create materials for campaign, including press release
- Mail solicitations
- Set up financial accounts

Deliverables

During this phase, we will complete several deliverables to help us raise funds and promote the foundation. These deliverables will help us develop a sustainable source of income, which will allow our foundation to be self-sustaining. Additionally, these deliverables will give us the means to inform others about our project. These deliverables include

- A mailing list of potential donors
- Public awareness of the foundation and its mission
- Mailing materials for fundraising purposes
- Accounts to protect foundation assets

Phase IV: Evaluative Procedures

During this ongoing phase, we will evaluate the foundation's progress towards its goals and report our conclusions to you, the National Eye Institute. To keep you informed of our progress, we will

- Draft and submit a progress report when the foundation lobbies Congress
- Record benefits of individual projects

Through this straightforward methodology, we will establish a stable, sustainable, and expandable foundation that will work to help Iowa's children with CEDs.

⁹ See Appendix B and Appendix F: Early Donations



QUALIFICATIONS

As previously shown, CEDs can cause a host of developmental delays for Iowa children. Hopara Consulting's unique qualities and experience with establishing successful nonprofit foundations will combine to create Eyes for Iowa. In particular,

- We are committed to Iowa families coping with CED
- We have implemented several successful comparable programs
- Our individual experiences and education underpin our strategy

WE ARE COMMITTED TO HELPING IOWA FAMILIES. As Iowans with families, the leadership team of Hopara Consulting is committed to establishing an organization that will use the ACE system to help Iowa families coping with CED. NEI's mission is "to protect and prolong the vision of the American people"; through its work, NEI helps establish "sight-saving treatments, reduces visual impairment and blindness, and improves the quality of life for people of all ages."¹⁰ Hopara Consulting's mission is simple: improving the quality of life for Iowans. Because both of our organizations are dedicated to helping people—Iowans in particular—our goals to help Iowa's children with CEDs is well-matched.

WE HAVE IMPLEMENTED SEVERAL SUCCESSFUL COMPARABLE PROGRAMS. In the past decade, Hopara Consulting has established several successful nonprofit organizations, including the following comparable organizations:

- The Literary and Arts Foundation of Greater Des Moines
- Project Learning Tree
- Hearts for Iowa
- ACORN

The Literary and Arts Foundation of Greater Des Moines was established in 1999 to work with inner city and poor children in the Greater Des Moines metro area through literary and arts education. Since its inception, 50% of high school students who complete LAF's program finish high school and earn a diploma. Further, 30% of these students went on to earn degrees from Des Moines Area Community College, Kirkwood Community College, ITT Technical Institute, Iowa State University, and the University of Northern Iowa.

Project Learning Tree is a nonprofit organization that provides educational access to single parent families in rural Iowa counties with fewer than 10,000 residents. The program works with these especially challenged parents to further their education and provide professional support services. Since its launch in

¹⁰ See "Mission Statement," *National Eye Institute*, National Institutes of Health, 4 December 2009, < <http://www.nei.nih.gov/about/mission.asp>>.



2000, over 500 parents have earned their High School Equivalency Diplomas. Another 450 parents have begun additional educational workforce training through distance education programs, and 43% of those parents have earned a two-year degree or trade certificate.

Hearts for Iowa, established in 2002, specializes in procuring treatment for children with congenital heart defects. Approximately 3000 babies are born in Iowa with congenital heart defects, and Hearts for Iowa works closely with the University of Iowa, the University of Minnesota – Twin Cities, and the Mayo Clinic to secure treatment and medical care for these Iowa children. Since 2002, 586 Iowa children have received low-cost treatment for a range of heart problems.

ACORN is a program that specializes in providing access for low income students with equipment and tutoring to improve math skills and scores. Established in 2007, ACORN works with first- and second-generation Latino high school students in Central Iowa. In two years, test scores for these students have increased by 10 percentage points with an anticipated 5-year increase of 25%.

HOPARA CONSULTING IS UNIQUELY QUALIFIED TO IMPLEMENT THIS PROGRAM.

Hopara Consulting will bring their educational foundations combined with their nonprofit and for-profit skills to Eyes for Iowa. Drs. [REDACTED] [REDACTED] are ready to commit their team and skills to Iowa's children with CED.

In particular, our professional qualifications combined present the background and experience that Eyes for Iowa requires:

- [REDACTED], MD, earned her medical degree from Johns Hopkins University specializing in pediatric genetics and defects. She is the co-founder and past director of Hearts for Iowa.
- [REDACTED], PhD, earned her PhD in Rhetoric and Professional Communication from Iowa State University. She is the past director of Project Learning Tree and currently serves as director and co-founder of ACORN.
- [REDACTED], earned his PhD in Rhetoric and Professional Communication from Iowa State University. As a parent of child with CED, he has lobbied Congress on behalf of children with CED for 5 years.

The following table denotes the roles and responsibilities of our personnel:



	Role	Responsibilities
██████████	Medical Director	Oversee medical component of Eyes for Iowa
██████████	Executive Director	Oversee project execution and larger scale issues and tasks of Eyes for Iowa
██████████	Program Director	Oversees daily operations of Eyes for Iowa and serves as liaison to National Eye Institute



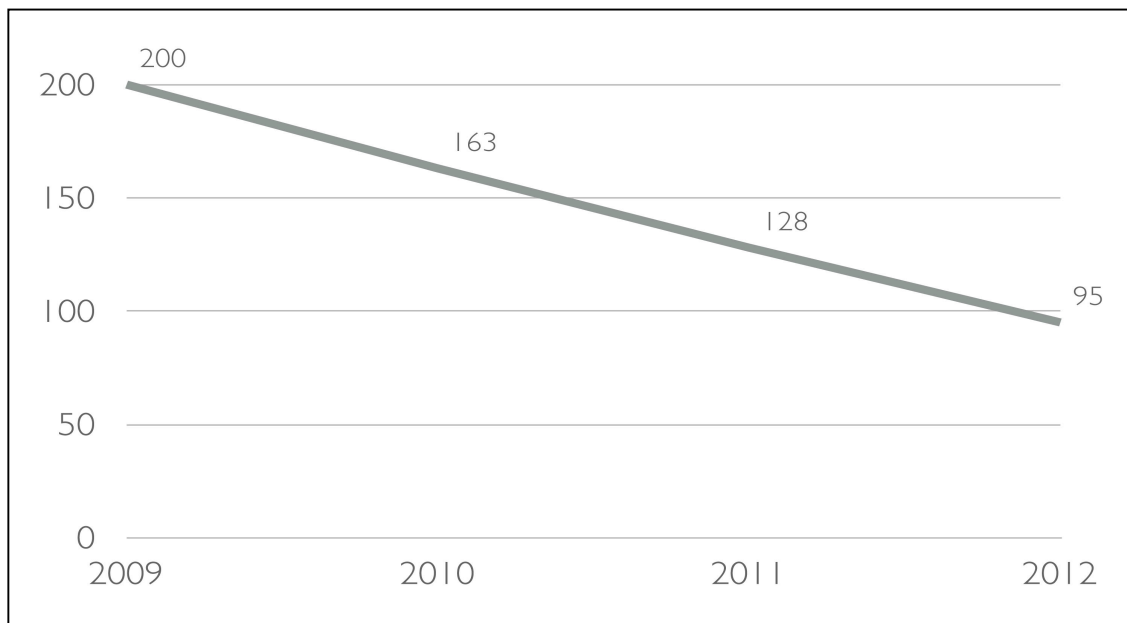
BENEFITS OF ESTABLISHING EYES FOR IOWA

Hopara Consulting is prepared to combine our methodology and qualifications to establish Eyes for Iowa. The foundation, once firmly established, will yield several benefits for Iowans:

- The number of children who become blind from untreated CED will be reduced by more than 50% by 2012
- Children with CED are more likely to meet 98% of major milestones by age 2
- Test scores of Iowa children with CED will increase by 30% over the next 10 years

THE NUMBER OF CHILDREN WHO BECOME BLIND FROM UNTREATED CED WILL BE REDUCED. Because of Eyes for Iowa, Central Iowa children will have more access to the proper medical treatment. As illustrated in Figure 3 below, more than 100 children will not go blind from CED within five years of the establishment of Eyes for Iowa.

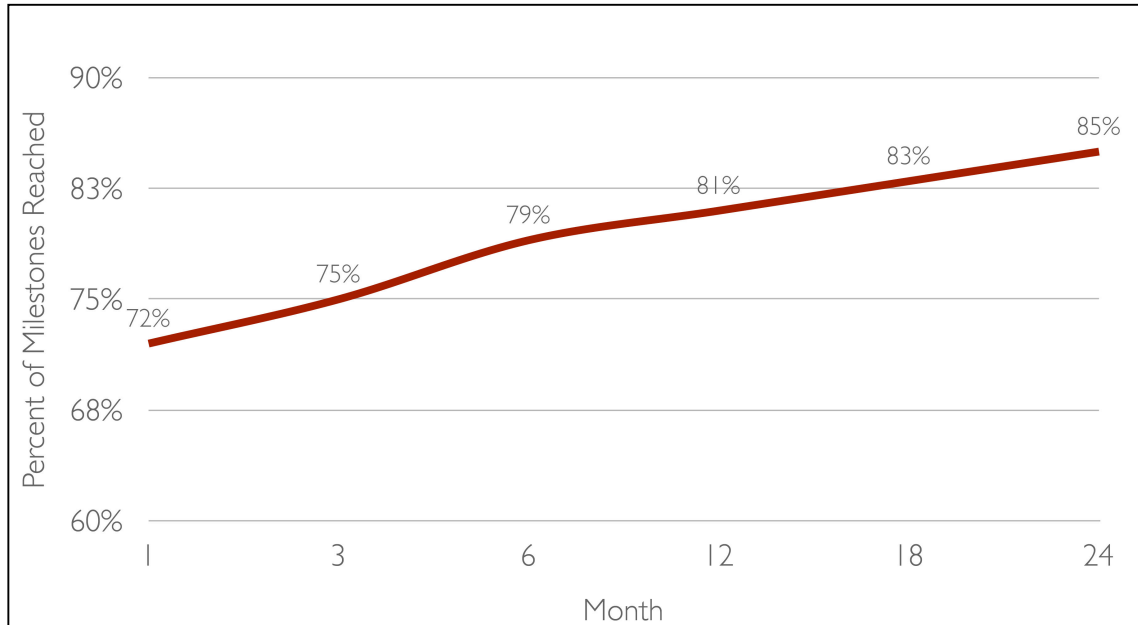
Figure 3: 100 fewer Iowa children will go blind from CED by 2012



CHILDREN WITH CED ARE MORE LIKELY TO MEET MAJOR MILESTONES BY AGE 2. Because of early intervention and treatment of CEDs, Iowan children suffering from a CED are more likely to keep up with their peers and meet major developmental milestones by age 2, as shown in Figure 4 below.



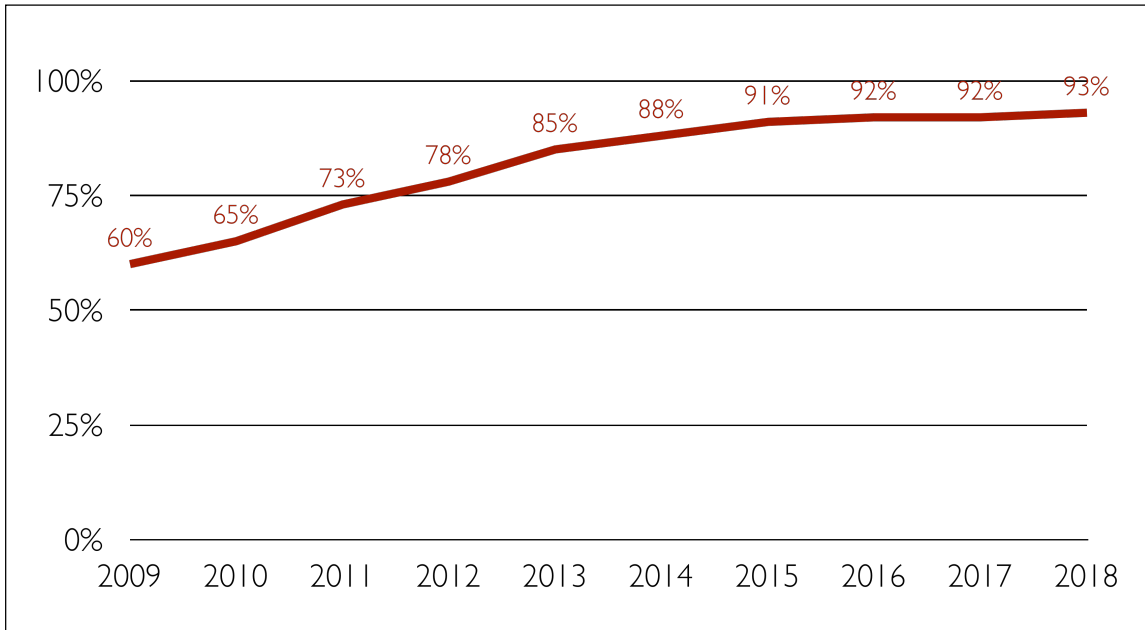
Figure 4: Children with CED will meet 85% of major milestones by age 2



TEST SCORES OF IOWA CHILDREN WITH CED WILL INCREASE. Through our program, children with CED will be able to better test. As shown in Figure 5 below, more Iowa children with CED will test at a proficient level in math and reading on the ITBS.



Figure 5: Test scores of children with CED will rise by 30% in 10 years



The early intervention and treatment of children with CED will allow those students to test at or above proficient levels in math and reading on the Iowa Tests of Basic Skills. Because of Eyes for Iowa, test scores of Iowa children with CED will increase by 30% over the next decade.

In short, Hopara Consulting is prepared to establish Eyes for Iowa, a nonprofit foundation that will benefit Iowa children with CED. Because 200 children in Iowa are born with a CED each year, Iowa families coping with CED need a group to advocate, coordinate, and educate (ACE) on their behalf. Our streamlined four-phase methodology will establish Eyes for Iowa as a sustainable, expandable, and stable legal and financial entity. Within five years of the establishment of Eyes for Iowa, blindness will be prevented in over 100 children with a CED. Further, Iowa children with CEDs are more likely to achieve expected developmental milestones by age 2. Finally, the test scores of Iowa children with CED will increase. Because of all these benefits, Eyes for Iowa will ultimately benefit Iowa's children and families.



**APPENDIX A: CHILDREN
WITH CONGENITAL EYE
DEFECTS, 2001–2005**



**APPENDIX B: RECEIVED
IN-KIND DONATIONS**



**APPENDIX C: MAP AND FLOOR PLANS OF EYES FOR IOWA
FACILITIES**



**APPENDIX D: ESTABLISHING HEARTS FOR IOWA, A CASE
STUDY**



APPENDIX E: TESTIMONIALS



APPENDIX F: EARLY DONATIONS