

Nominate Your Passion

Grant Proposal Application

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Which UN Millennium Goal does this proposal utilize? You can check more than one.

End Poverty and Hunger Universal Education Gender Equality Child Health
 Maternal Health Combat HIV/AIDS/malaria **and other diseases** Environmental
Sustainability Global Partnership

Where is the project located? Boston

Is this a registered charity with a 501-c3 united States Tax Code? yes

Project Description Form

Project Name: *Walk in my Shoes* : an anthology of 27 inspiring stories written by people affected by Usher syndrome, *the most common cause of combined deafness and blindness in the world*. These stories will alter your perspective on human emotional and physical strengths.

Project Contact Person: Charlotte DeWitt, Executive Editor/Business Manager

Project's Address:

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1. Date the project was established:

The Usher Syndrome Coalition was founded in 2010. Usher syndrome is *the most common cause of combined deafness and blindness in the world*. It is transmitted genetically. There is no cure. Planning for the anthology *Walk in my Shoes* was initiated by a group of enthusiastic volunteers in early 2015, and by March 3, 2015, an Executive Committee had been formed, a project outline developed, and prospective authors invited. Most of the participants are deafblind.

2. Describe the project, its purpose or mission, and the “Parent or Umbrella” organization (if any) administering the project? (For example, The Salvation Army, UNICEF)”

Imagine that you are born without hearing and learn that you will also lose your sight. Imagine the

isolation, the fear, and the limitations on your life. Imagine being the parents of such a child.

Walk in my Shoes is a collection of real-life stories written by twenty-eight deafblind authors who have Usher syndrome or by family members of those who have the disease. Geographically, they live throughout North America, principally in the United States, with one writer in Canada and one in Mexico. The purpose of the book is to inform and to educate and, on an emotional level, to end the loneliness associated with the disease. Each story is inspiring and breaks stereotypes regarding Usher syndrome by showing that it is possible—not easy, but possible—to have a happy and fulfilling life while waiting for scientists to find a cure. These stories offer a glimpse into the challenges of living with Usher syndrome, demonstrating how those with the disease overcome obstacles daily while dealing with their dual sensory loss. These are real people living real lives and extending the offer of sharing how they did it with others. This is the story of their “normal”—their desire to be meaningful and respected members of their communities. You will never feel the same after reading these stories of hope and accomplishment.

In addition to personal stories, the book has two appendices, written for the layman. Appendix A gives an overview of the disease, and Appendix B is a comprehensive list of resources and agencies helpful to those with Usher syndrome, including contact information for the Usher Syndrome Coalition.

Walk in my Shoes has been endorsed by the Helen Keller National Center, prominent doctors, researchers, educators, and national and international advocates for Usher awareness.

The book will be published in several formats to accommodate the needs of its readership: digital, which allows for adjustable font size and optional reverse-color appearance (yellow or white letters on a black background), and is easily accessible online both here and abroad; print, for those with adequate vision, with particular attention being paid to the choice of typeface and font; braille; and audio for those with hearing but limited or no vision, such as Usher people with cochlear implants. Special arrangements have been made with state libraries throughout the United States to provide ***Walk in my Shoes*** in braille and audio formats as a complimentary gift to the deafblind community upon request.

The goal of ***Walk in my Shoes*** is to share stories of living with Usher syndrome so as to inspire, raise awareness and educate others about the disease; build empathy through sharing these stories; demystify the disease; and through the sale of the book, to raise money for scholarships for people with the disease to attend the annual Usher Syndrome Family Conference—in short, a self-help program by Usher authors helping others affected by Usher syndrome. The authors unanimously wish to donate all net profits to the Usher Syndrome Coalition for scholarships to its annual conferences.

Umbrella Organization

The Usher Syndrome Coalition, in cooperation with the ***Walk in my Shoes*** Executive Committee

The Usher Syndrome Coalition's mission is to raise awareness and accelerate research to find a cure for this disease. The Coalition also provides information and support to individuals and families affected by the disease and produces an annual Usher Syndrome Family conference in the United States, as well as an international research conference every five years bringing together top scientists searching for a cure. The 2017 Usher Syndrome Family Conference will be in Chicago; the 2018 international research conference and family conference will be in Germany. Linking this all together is the international Usher

Syndrome Registry initiated and managed by the Coalition. It includes those diagnosed with Usher syndrome, as well as Usher families and friends, medical professionals, and researchers, and serves as a resource for those interested in participating in clinical trials to find a cure, as well as a source of networking.

3. How did you hear about this project and how have you supported it?

I have wanted to write a collaborative book on Usher syndrome for several years. Born totally deaf, diagnosed at age 4, and now legally blind at the age of 34, my nephew Randall DeWitt, in spite of all odds, has two university degrees and has overcome all sorts of barriers. I wanted to help him tell his story, to see himself as a leader rather than a victim, and I wanted his mother to tell hers. Both are inspirational in their own ways.

In 2015, word of this got to Ramona Rice, a person with Usher syndrome living in Utah. She had a larger vision: to invite many Usher people to collaborate on a book. She invited me to be a part of this project. The end result was a steering committee consisting of Ramona as project leader, myself as Executive Editor and Business Manager, Randall's mother Karen Duke as Secretary and Social Media Manager, and Randall as an Editor. Randall is deeply committed to serving on the book's Executive Committee, as well as participating as an author and an editor of chapters written by authors who communicate in American Sign Language, which reads like a foreign language written in mysterious, incomprehensible English. I want to help him and others like him. It is a race against time to find a cure, but in the meantime, I have found an extended family in these authors and a positive way to use my skills to contribute to the greater good.

In what specific way have you supported this project?

My professional career for the past 38 years has been producing national and international events, such as the Millennium finale of Singapore's Chinese New Year's celebration. I also produced the 2003 FAWCO Conference in Stockholm attended by HM Queen Silvia of Sweden; helped with the 2010 FAWCO Conference in Boston, hosted by FAUSA; and have served as the New England Regional Representative for FAUSA for several years. I am also a published author with an international readership. I have worked in 30 countries since 1979.

I had previously volunteered my professional services for two years (2012-2014) for the 2014 Usher Syndrome Coalition's conference at Harvard Med School in Boston, featuring both an international research component as well as a family conference.

It seemed appropriate, then, to continue to volunteer my professional services for nearly two years as the Executive Editor and Business Manager of *Walk in my Shoes*, 2015-present, to help these deafblind authors succeed in publishing their stories and raise money for scholarships to Usher syndrome conferences. As one of the few people with normal sight and hearing involved in this project, I've edited, proofread, helped develop the business and marketing plan, worked with our self-publishing consultant and graphic artist, done fund raising, and assisted in the ongoing management of the project.

It is very time-consuming and moves slowly because we are working in a dark, silent bubble, myself included—but it is well-worth the involvement.

4. Please provide information regarding staff of the proposed project (size of staff, number of paid staff, number of volunteers, etc.):

The core staff of *Walk in my Shoes* is an Executive Committee of four volunteers plus a volunteer

graphic artist and a volunteer editor, most of whom have Usher syndrome. As Executive Editor/Business Manager and one of the few volunteers with normal hearing and sight, I am working directly with Merrimack Media, a Boston-based private company specializing in self-publishing and marketing. They have been very generous in their pricing and delayed terms of payment.

Additionally, some of the resources of the existing Usher Syndrome Coalition staff will be utilized, as needed, to support this project via their website, newsletters, and eventually, the distribution of our scholarships. Coalition staffing includes:

Paid staff:	2
Board of Directors:	12
Volunteers:	20-50
Student interns:	3
Pro bono legal help	2

5. How will the grant be used and how will it benefit the community?

Walk in my Shoes will be self-published by its authors, with all net profits donated to the Usher Syndrome Coalition, a 501(c)(3) corporation, for the purpose of scholarships to its annual family conferences. FAUSA funding will be used to hire a private company specializing in helping authors self-publish and promote their books, as this would be too difficult for deafblind people to undertake themselves. The \$2,575 agency fee includes a 10% charitable discount. FAUSA funding will be augmented by loans from the authors, who in turn, may have to borrow this themselves. Due to both deafness and blindness, most people with Usher syndrome are unable to hold down paying jobs and live on nominal social security incomes.

This project draws on the in-kind skills of pro bono editors, sighted proof-readers, project managers, fundraisers, marketing specialists, and lawyers.

Fees/travel expenses to attend, present, and/or exhibit at deafblind-related conferences/conventions/DB community gatherings, will be individually self-financed by the authors, or sponsored. To put this in perspective, however, keep in mind that American Sign Language interpreters' fees, either for visually signing or tactilely signing into the hand, run around \$55/hour, and the interpreters work in teams of two (therefore \$110/hour), alternating every 15 minutes, as it is too intensive for one person to do interpretation non-stop. As much as these authors may wish to participate in "selling" this book, they face limitations.

Crowd-sourced funding may also be considered via internet appeals, but with the understanding that this is physically extremely challenging for a deafblind person to do independently of any help.

All participating authors have agreed to donate their share of any net profits to the Usher Coalition Scholarship Fund.

Benefits to the community

Multiple communities benefit from this project: the deafblind community, the geographical communities in which these people live, the medical community, and that of educators.

People with Usher syndrome and their families exist in a community unique to their disease. Since there is no cure, news of a diagnosis can be devastating, and the end result is still the same: isolation—socially, intellectually, emotionally, and professionally. Depression and thoughts of suicide are not uncommon.

- The rate of risk of suicide attempts among people with Usher syndrome is up to 6 times greater compared to the general population. (Wahlqvist, 2013)
- 61% of deafblind individuals have reported high rates of psychological distress, a state of emotional suffering characterized by symptoms of depression and anxiety, compared to 34% in the general population. (Bodsworth, 2011)
- 60% percent of people with Usher syndrome refrain from going out alone, compared to 25% in the reference group. The difficulty in going out independently contributes to the social isolation experienced by many in the Usher community. (Wahlqvist, 2013)

Walk in my Shoes authors write to change these statistics by sharing examples from their own lives. Here are some of the benefits to the Usher community:

Employment

Usher victims face unemployment rates that rival those of 3rd world countries – the most recent study documented an 82% unemployment rate for deafblind youths age 18-24, with only 47% of them graduating from high school even after staying in school until the maximum allowable age of 20 for free education. An estimated 45,000 Americans have the disease, with an estimated 400,000 worldwide.

This book gives some members of the deafblind community the opportunity to be self-employed as authors and to make a positive contribution to their own DB community. It is their choice not to receive royalties they would otherwise be entitled to.

Emotional support

The greatest immediate benefit to the deafblind community is an end to isolation. The tone of ***Walk in my Shoes*** is positive and up-beat and presents role models via those who are proactively coping with the disease and making a difference. For families terrified of what awaits them and their children, the anthology offers inspiration, wisdom, and hope.

Education

The third benefit is educational.

For members of the deafblind community, the book contains two appendices with useful information about the disease and resources that can help those living with the disease or recently diagnosed.

Walk in my Shoes will also educate the medical community, patient advocates, and other providers with real life stories, resulting in improved health, both psychological and physical, for those with Usher syndrome.

Finally, members of the political community on local, state, and national levels will be better sensitized and informed about the disease.

How many people will receive aid or be directly impacted by receipt of this grant?

What is the value of one life saved? What is the value of quality of life, of freedom from depression due to an incurable, insidious disease that, at its worst, leaves people in a totally soundless, sightless world between the ages of 15 and 50? Suicide is not uncommon.

An estimated 400,000 people in the world have Usher syndrome. Approximately 45,000 of these are in the United States. If the real life stories of achieving happiness and well-being in this book can give a fraction of these people hope and rescue them from isolation, this book will have accomplished a lot.

Anticipated readership includes not only those with the disease, but also family members, friends, researchers, educators, doctors and professional caregivers, and scientists. The book also will impact politicians, funding agencies and foundations, journalists, and members of the general public who are interested in such iconic people as Helen Keller and Stephen Hawking. The book will give these readers emotional insights into Usher syndrome that could help them do their jobs with more sensitivity, thereby affecting the quality of life and the health and education of those with the disease. On a political advocacy level, the book will humanize the plight of those with Usher syndrome and hopefully lead to government funding of research for a cure. Currently there is none.

Those directly benefiting from the sale of the book from a financial standpoint will be scholarship recipients to the annual Usher syndrome conference.

Strategically, we will start our outreach efforts via two channels: a campaign directed by Merrimack Media using its established relationships with publishing companies like Amazon.com and its own website and PR contacts; and via our own marketing campaign to the 2,000 people on the Usher Coalition mailing list, as well as via the Coalition website and social media platforms like Facebook and Twitter. From the initial 2,000 we will reach out via press releases to print and broadcast media, face-to-face meetings at conferences, conventions, deafblind organizations and deafblind social groups to make it easy for them to buy the book. With the help of the National Association for the Deaf, we also are developing targeted lists which include its national deaf/hard of hearing and deafblind agencies, organizations, and associations. We also will be publicized nationally through state library systems, which will notify their constituencies that braille and audio copies are available.

6. In one year how will the grant's impact on the project be measured?

Funding is needed to move the book publication forward. Once published, the FAUSA investment can be measured by the number of books sold and how many scholarships to the annual Usher Syndrome Family Conference were funded from the net proceeds. The Coalition will award the scholarships. The intangibles of helping people envision a meaningful life are harder to measure.

Social media responses can also be monitored. There are several Usher syndrome related Facebook accounts including that of the Usher Syndrome Coalition.

Attendance at the 2017 Usher Syndrome Family conference in Chicago can be compared to previous "stand-alone"/non-research conferences, such as the 2016 Usher Syndrome Family conference in Seattle, which had 200 attendees, or the 2015 Family Conference in New Orleans, which had 170 attendees. Awareness of the annual Usher conference should increase due to publicizing the book and the scholarships, and increased awareness should result in increased attendance.

Please provide the name, address, telephone number and E-mail information of the person who will be responsible for providing the one year achievement information to FAUSA.

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Table of Contents

Introduction

Chapters

1. Diagnosis: learning, accepting, living with Usher syndrome

THROUGH LILLY'S EYES: A MOTHER'S INTERPRETATION by Angela Diuble

A young mother tells of her daughter Lilly's Usher diagnosis and their journey to raise awareness and raise funds for research.

MY JOURNEY TO AN USHER DIAGNOSIS by Laura Rough (USH 2A)

A delayed diagnosis propelled this author into political activism so others would not have to wait for help.

MY LITTLE SECRET by Randi Knutson (USH 2)

The challenge... and stress... of hiding Usher from family and friends. Early onset blindness at age 22.

LIFE WITH A LATE USHER DIAGNOSIS by Marisa Herrera Postlewate, PhD (USH 2A)

A native of Madrid, Spain, this author's Usher condition went undetected for years because she was so good at coping. Educated in the UK and the US, she continues to inspire with her many achievements.

2. Life in an Usher Family

FEARING THE UNKNOWN by Anna Sengillo (USH 2A)

A mother talks about the difficulties adopting a child as an Usher parent, raising two children, and learning to live life to its fullest.

LIFE WITH A MOM WHO HAS USHER SYNDROME by Jesse & Candice Sengillo

Anna Sengillo's two children share their stories, both humorous and compassionate, about life with their Usher mother.

MY LIFE ADJUSTMENTS WITH USHER by Jenni Thompson (USH 2A)

From a diagnosis of deafness at age 2 to impending blindness as a single mother with both Usher syndrome and Coats Disease at 23, Jenni trains for a new career and refuses to give up. This is a story with a very happy ending.

A CHILD'S POINT OF VIEW by Cheyenne Thompson

As her mother loses more sight and hearing, Jenni Thompson's 15-year-old daughter finds inspiration and a role model on being strong ... even though she, too, could have a child with Usher syndrome in later life.

SCALING MOUNTAINS by Melissa Chaikof

Continued next page...

The mother of two USH1F girls talks about exploring communication alternatives... and making medical history.

SEARCHING FOR THE LIGHT IN THE DARKNESS by Jessica Chaikof (USH 1F)

The youngest person ever to receive a cochlear implant writes of her challenges from Girl Scout camp to college chemistry classes.

IT'S ALWAYS CHRISTMAS by Karen Duke

With great humor and insight, a mother shares her interior decorating tips adapting her home to make daily life easier for her adult Usher 1 son.

3. Independent living

THE BLINDING DRIVE AND BEYOND by Sonya Marney (USH 2A)

A young woman driving a Camaro sports car at night suddenly cannot see and must come to terms with coping with Usher... or else.

BEING INDEPENDENT WITH USHER by Diana Velarde (USH 2)

"I come from a family where all women are warriors, and I intend to do the same," writes the author, a native of Mexico. Bi-lingual in English and Spanish, she shares her tips on how to adapt as an international IT professional, and how to succeed in living a fulfilling life in spite of Usher and Retinitis Pigmentosa.

TRANSITIONING WITH USHER SYNDROME by Sharon James (USH 2A)

"Would you rather be blind or deaf?" was a survey question in junior high school. Years later, with the help of a leader dog, the author makes the transition from living sighted to being deafblind.

THE POWER OF THE CANE by Randall DeWitt (USH 1)

Who says cane training can't be funny? Some of the most unique ideas ever on what to do with a white cane.

TEN THOUSAND MILES FROM HOME by Leland Miller

A congenitally blind student graduates and chooses to relocate so as to teach geographically isolated Usher 1 people orientation and mobility skills.

INDEPENDENCE DAY by Charlotte DeWitt

Ever curious, the aunt of an Usher 1 man tries her hand as a deafblind person with a white cane on the 4th of July to show the obstacles and often impossible accessibility issues present in the city of Boston. The hurricane was extra.

4. Professional life as an Usher person

WHEN ONE DOOR CLOSES by Amy Bovaird (USH 3)

A teacher of English as a Second Language repatriates after an overseas posting and re-invents herself as an exhibitor in arts and crafts shows in America.

MY USHER'S LIFE LESSONS by Mary Dignan (USH 2)
A successful attorney adapts, with humor, to a new life.

REDEFINING INDEPENDENCE AND EMPOWERMENT by Roberta Giordano (USH 2C)
The author reflects on the 9,280 days since she was first diagnosed with Usher syndrome, her career as a school psychologist, and the pivotal moment of giving up her driver's license.

AN ODYSSEY THROUGH USHER by Mani Iyer (USH 2)
An IT professional moves overseas and shows how access to transportation is the key to professional advancement.

STEPPING STONES by Audrey Chard (USH 2)
After intensive mobility training wearing blinders to learn self-confidence using a white cane, a brave young woman moves to China to teach in an orphanage.

5. Inspiring Tales: Who says I can't?

RACING AGAINST TIME by Ramona Rice (USH 2)
A bank manager tackles the onset of deafness and blindness by defiantly founding a social club for Usher women, producing conferences for the blind, influencing politics at the state level, and initiating this book project—all while dealing cheerfully and positively with major health issues of her own. "No" is not in her vocabulary, and she never quits.

HOW TO GET A MINOR IN A FOREIGN LANGUAGE WHEN YOU HAVE USHER by Brian Switzer (USH 2)
A young college graduate gets lost in Germany and survives using his new language skills powered by an invincible, can-do attitude.

TETHERED IN STRIDES by Rose Sarkany (USH 2A)
An artist, photographer, copy writer, and marathon runner, this spunky author's motto is "My horizon is broader than my tunnel vision." She urges all to "Walk in my Shoes."

MY SELF-DISCOVERY OF USHER SYNDROME by Stephen Ehrlich (USH 1)
Orphaned at birth, now totally deaf and blind, the founder of Seabeck, the annual deafblind recreational camp in Seattle, Washington state, discusses the challenges of coping with life difficulties imposed by the reduction and/or loss of five essential values.

MY DEAFBLIND LIFE by Elaine Ducharme (USH 1)
The founder of the Deaf Blind Community Action Network (DBCAN) in Boston and the Deaf Blind Association of Connecticut has never let her lack of sight or hearing keep her down. She communicates primarily via tactile signing and the infectious warmth of her personality.

Acknowledgments

Appendix A: Introduction to Usher syndrome

Appendix B: Resources