Hypertrophic Cardiomyopathy Centers of Excellence

United States
Lisa Salberg

Project Summary

Elevator Pitch

Concise Summary: Help us pitch this solution! Provide an explanation within 3-4 short sentences.

Hypertrophic cardiomyopathy (HCM) is the most common type of genetic cardiovascular disease. Approximately 600,000 or one in 500 persons in the US have HCM; many do not even know it. The clinical manifestations of HCM vary and range from asymptomatic to congestive heart failure, stroke and even sudden cardiac death, especially in the young. Symptoms may occur at any age. The average age for women diagnosed with HCM is 38 while the average age for men is 34.

HCM is one of the most misdiagnosed types of heart disease in the country, leaving many with an uncertain fate. It takes trained cardiologists to diagnose and treat HCM that left alone may lead to disability or early death. In 2002, the HCMA and Tufts New England Medical Center in Boston developed an HCM Center of Excellence. This partnership is leading the way how HCM is diagnosed and treated. Today, the Tufts program has evaluated of over 350 patients.

The need for additional services for HCM patients came in part as a result of the closing of the National Institutes of Health (NIH) HCM program. For over 40 years, the NIH conducted research into the disease. All patients with HCM were potential candidates of the NIH program. They would receive diagnosis and possible treatment at the NIH including surgery and participate in a variety of trials. In the early 2000s, the NIH ended its program leaving patients without any specialists with experience in HCM.

By assembling a team of cardiologists trained in HCM at Tufts along with state-of-the-art technology and treatment options, patients in the northeastern US are able to receive appropriate care. Today, the HCMA works with 14 HCM Centers of Excellence at major hospitals and university healthcare centers across the country as well as three in Europe. Not only do these regional centers provide accessibility, they also reduce costs associated with the amount of unnecessary tests conducted by physicians and cardiologists unfamiliar with HCM.

About You

Location

Focus of activity

Year the initiative began (yyyy)

2002

Positioning of your initiative on the mosaic diagram

Which of these barriers is the primary focus of your work?

Patients not empowered

Which of the principles is the primary focus of your work?

Center consumers in business model

If you believe some other barrier or principle should be included in the mosaic, please describe it and how it would affect the positioning of your initiative in the mosaic:

This field has not been completed

Innovation

Define the innovation

Hypertrophic cardiomyopathy (HCM) is the most common type of genetic cardiovascular disease. Approximately 600,000 or one in 500 persons in
the US have HCM; many do not even know it. The clinical manifestations of HCM vary and range from asymptomatic to congestive heart failure, stroke and even sudden cardiac death, especially in the young. Symptoms may occur at any age. The average age for women diagnosed with HCM is 38 while the average age for men is 34.

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Context for Disruption:

Healthcare consumers are demanding better healthcare across all disciplines. The HCM Centers of Excellence address these demands by providing teams of trained medical personnel and diagnostic technology such as a cardiac MRI and genetic testing. The investment in developing a Center reduces misdiagnoses, improves the quality of life for patients and their relatives who may also have the disease, and reduces the costs associated with physicians ordering inappropriate diagnostic testing and procedures because they are not familiar with HCM.

There are barriers to receiving appropriate diagnosis and treatment for HCM as found in a recently completed survey of 610 randomly selected cardiac medical professionals conducted by the HCMA. The survey found that even among these specialists, only 14 percent were able to correctly identify the six risk factors for cardiac arrest and HCM. Only 54 percent of the respondents correctly answered the question: how often should a child within a family with a member diagnosed with HCM be screened for the disease? The correct answer is every 12 months.

It takes approximately two years for a Center to achieve significant patient volume. In the case of the Center at the Hypertrophic Cardiomyopathy Clinic at the University of Michigan that began in April 2006, within six months they had 30-50 patients. As of July 2007, they now have a roster of over 100 patients.

HCM Centers of Excellence provide teams of professionals who know and understand the disease. Each Center has cardiologists trained in HCM. At each Center, the multidisciplinary team of cardiologists take as much time as necessary with each patient to ensure the best possible physical and mental care of the patient. This goes against the norm of no more than 15 minutes per patient.

The demand for the Centers continues to grow. HCMA plans to open six additional HCM Centers of Excellence over the next three years.

Delivery Model

It takes awareness building and consumer empowerment to generate patient volume at an HCM Center of Excellence. Each Center worked with the HCMA to increase public awareness, conduct patient education, and encourage physician referral. The pubic awareness campaigns generated by the HCMA and the Centers put the decision of care in the hands of the patient.

Specific communications channels used to promote the Centers include, but not limited to: information to cardiologists in the catchment area; public service announcements; news releases to all media outlets; cardiologists from the Center speaking at area health conferences and public gatherings; educational materials distributed at area health fairs and events; information published on the HCMA and Center’s websites; referrals from the HCMA who makes on average 105 referrals per month to the Centers; and informational sessions at conferences on HCM for cardiologists every three years, the next one takes place in 2009. It was at the 2006 HCM Conference at the Minneapolis Heart Institute that cardiologists affiliated with the Cleveland Clinic and the Mayo Clinic referred to the advocacy of the HCMA as the HCMA Factor. As the HMCA increases awareness of HCM, patient volumes at the Centers increase exponentially with many doubling even quadrupling over the last three years.

There are 14 HCM Centers of Excellence: the Mayo Clinic, the Minneapolis Heart Institute, the Cleveland Clinic, Tufts New England Medical Center, Brigham and Women's Hospital/Harvard Medical School, St. Luke's Roosevelt Hospital in New York, the University of Texas Health Science Center in San Antonio, Northwestern Memorial Hospital's Bluhm Cardiovascular Institute, University of Michigan Cardiovascular Center's HCM Clinic, Washington University HCM in St. Louis, the HCM Center at Stanford University, the Heart Hospital in London, Italian HCM Institute, and the Study Group on HCM also in Italy. For future sites see scaling up section.

Key Operational Partnerships

The Centers of Excellence were chosen because of their reputation in the field of HCM. While all are major healthcare facilities, it is their dedication to HCM that made them ideal candidates. The 14 Centers not only have trained medical personnel, they also have the resources to dedicate to a facility for the diagnosis and treatment of HCM.

As identified in the previous question, all of the Centers are major healthcare institutions, many affiliated with universities. At a minimum, each Center must have a cardiologist with specialized training in HCM. They must also have cardiologists that serve adults and children as well as an electrophysiologist, cardiac surgeon(s), and access latest diagnostic technology and laboratories. Each Center must be able to designate space including a reception area, waiting room, and patient rooms. The hospital or healthcare facility manages the Center. The HCMA facilitates the development of the Center and provides consultation, marketing, referrals, and patient education support.

With the closing of the NIH HCM program, these Centers are the lifeline for patients with HCM. All provide regional access for patients and their families, usually within a five-hour drive one way. Without these Centers, patients with HCM, even those that do not know they have the disease, may experience avoidable disability or death. The HCMA maintains a reciprocal relationship with the Centers by providing patient education and referrals.
HCMA does not earn revenue from the HCM Centers of Excellence. Costs associated with operating the Centers come from the healthcare facilities themselves, third-party insurance providers, and charitable care resources to ensure that those patients without healthcare insurance receive services. HCMA is responsible for the costs to create an HCM Center of Excellence such as staff time, marketing, and the development and distribution of the patient educational materials.

What is your annual operating budget?

$170,000

What are your current sources of revenue? (please list any sources that are foundation grants)

The HCMA receives funding from a number of sources. These include private donations, memorials, special events, and annual grants. Current foundation grantmakers include: the Medtronic Foundation, Severns Family Foundation, Boston Scientific, and the Elizabeth McNamee Memorial Fund. Grants comprise less than 30 percent of the HCMA annual budget.

Effectiveness

There are five measurable outcomes as a direct result of opening the HCM Centers of Excellence.

1) Reduced incidence of early death caused by HCM through improved care and awareness.
2) Improved the quality of life including mental well-being of patients diagnosed with HCM.
3) Increased overall patient knowledge about living with HCM.
4) Reduced costs relating to proper diagnosis and treatment of patients with HCM.
5) Increased perception of value of the healthcare institutions by the community for making HCM Centers available.

In a recently completed survey of 703 patients with HCM by the HCMA, 46.5 percent reported being seen by an HCM specialist. Of this percent, 78 percent visited a Center referred by HCMA. Ninety percent of the total respondents stated that their insurance provider covered all costs. Healthcare coverage continues to be one of the reasons why patients do not pursue care. This is why the Centers offer charitable care for patients with HCM.

In 11 years, HCMA has been instrumental in opening 14 Center of Excellence in the US. Because of the availability of these Centers, over 7,000 patients have been diagnosed with HCM and learned to manage their condition. On average, HCMA makes over 100 patient referrals per month to the Centers. This means that of the estimated 600,000 persons living with undiagnosed or misdiagnosed HCM, the HCMA has only begun to make an impact on the health and well-being of patients and their family members.

It is because of the Centers and the advocacy of the HCMA that HCM is no longer an orphan disease. Now other healthcare institutions across the country want HCMA to help them develop a HCM Center of Excellence. The impact of starting the first Center at Tufts has now spread across the country and into Europe. Fellow healthcare institutions see the incorporation of an HCM Center as a good business model that places the healthcare institution above all others in its service area.

Which element of the program proved itself most effective?

The goal of the HCM Centers of Excellence is to provide comprehensive care of patients and families with HCM. Saving the life of anyone with HCM or misdiagnosed heart disease is the reason these Centers exist. Literally, thousands of lives have been saved since the HCMA began working with its current roster of partners. All of the Centers comply with the medical management standards of care for HCM.

The greatest and most effective component of operating the Centers is the sheer volume of new patients diagnosed with HCM while reducing health costs. All of the services for patients and potential patients are under one roof. This saves time and money for both the patient and the insurance provider. Instead of patients going back and forth to their primary care physician and/or cardiologist then to another facility for testing that will take sometime to receive the results, patients visiting a Center see a specialist with in-house diagnostic services, and are provided with an immediate diagnosis and prognosis. The cost of performing unnecessary tests to identify the cause of their health condition is eliminated. Even if the patient does not have HCM, they will still have answers to their health condition if not by the multidisciplinary team of medical professionals at the Center, then by another department within the healthcare facility or hospital.

By having dedicated and highly trained staff members to thoroughly evaluate patients then provide treatment, the Centers prove to be highly effective. Each maintains high quality standards, a commitment to putting the patient first, conducting research and publishing their results, and advocating for the improvement to the general care and management of patients with HCM.

Number of clients in the last year?

Each Center sees on average 100 to 500 patients each year. The HCMA has recorded over 3,500 unduplicated or unique families with HCM. Within each family, there can be one to 10 relatives also with HCM. The HCMA and the Centers have only begun to bring awareness of HCM to the general population. As awareness builds, so will the number of new patients diagnosed with HCM.

The Centers can provide initial diagnosis through referral by a cardiologist or by the patient themselves. Each Center provides standard physicals along with electrocardiograms (ECGs) and echocardiograms to assess the patients’ risk and determine best course of treatment. Treatment options may include medication, surgery or the implantation of a pacemaker or defibrillator.

The HCM Centers provide the opportunity to treat patients and families with hypertrophic cardiomyopathy using a multidisciplinary team that addresses the unique needs that a complex disease such as HCM presents. Patients will see by an average of three physicians, all of whom have extensive experience in the management as well as continuing study and research of HCM. Through this approach patients will benefit from the individual experience and expertise that the physicians and staff of the Center provides.

What is the potential demand?

HCM is a disease primarily of an abnormal enlargement of the heart muscle. It is a genetic disease that runs in families and is not preventable. If a patient is diagnosed with the disease, most often their children or siblings also have HCM. It is important to educate the general population about HCM. Patients need to be able to make choices about their care and have access to resources and specialized services like the those offered by the Centers.
There is no particular symptom or complaint that is unique to HCM. Symptoms may occur at any stage in a person's life even though the condition may have been present for some time. The reason for the onset of symptoms is often not clear. Patients with HCM often have complaints of symptoms such as shortness of breath, exertional dyspnea, lightheadedness, and chest pain. These are also symptoms for other types of heart disease such as mitral valve prolapse or even asthma. That is why proper diagnosis by trained cardiologists is so important to the health and well-being of patients with HCM. The majority of patients with symptoms can be treated with pharmacological therapy.

Today, there are over 600,000 people living in the US with HCM, either diagnosed or undiagnosed. Many do not know they even have heart disease. Even if they see their primary care physician and are referred to a cardiologist, the cardiologist may not be trained in HCM. Over the years, many patients with HCM die because of misdiagnosis or improper care. There is a great need for regional HCM Centers to ensure that all patients with mysterious heart conditions have a place where they can get answers to their questions and begin receiving proper care.

Scaling up Strategy

The vision of the HCMA is to eventually have an HCM Center of Excellence in every state. Over the next three years, it will develop six new HCM Centers of Excellence in the following states: southern California, Kansas, Maryland, Nebraska, New Jersey, and Washington. These Centers will serve large metropolitan areas as well as persons with HCM or misdiagnosed heart conditions within a five-hour drive. The HCMA is already in discussions with qualified healthcare institutions in five of the states.

The HCMA selected these states because of the numbers of inquiries it receives regarding referrals. Currently, the 14 Centers located in the US serve primarily the Northeast, northern California, the Midwest, the Upper Midwest, and Texas. Coverage is lacking in the Pacific Northwest, southern California, the Central Midwest, Mid-Atlantic, and the Mountain Region. For patients to receive services from the HCM Centers, they have to bear great expense for travel.

The first priority is to select potential partner healthcare institutions. The model HCM Center needs to be an academic or large regional healthcare center with a reputation for excellence. The healthcare institution must be able to conduct research to improve the health of patients and family members with HCM. The potential partner must possess specialists in adult and pediatric cardiology, adult and pediatric electrophysiology, cardiac surgeon(s), cardiac MRI, cardiac echocardiography, interventional cardiology, genetics, dietitian, access to social services, and the ability to see family members with possible HCM at one time. These are demanding requirements, but all necessary to qualify as a Center of Excellence.

Stage of the initiative:

1

Expansion plan:

The development of a Center takes approximately two years to complete. Each healthcare partner must take steps to integrate the philosophy of care for HCM patients into its existing cardiology programs. This includes hiring a cardiologist with training in HCM. It must also have access to the required diagnostic technology and laboratory as described earlier.

Each Center begins slowly by providing one clinic day per week to see HCM patients. At this early stage of development, there are very little capital costs associated with the development of the Center. As the program grows, each Center can increase the number of available patient slots as well as personnel.

Still with the addition of the six Centers, coverage for patients with HCM will be continue to limited in the south, southeast, and southwest. HCMA will begin developing relationships with healthcare institutions and hospitals in these areas to launch Centers by 2013.

In addition to patient support and referral, the HCMA is in the process of creating a registry of physicians specializing in the care of HCM. This will allow the HCMA to make referrals to patients where Centers are not easily accessible.

Origin of the Initiative

HCMA Founder, Lisa Salberg, has HCM. She has lost 4 family members under the age of 52 to HCM. Her sister was 36 when she died of cardiac arrest. Those living with HCM include her niece who was diagnosed with HCM at age nine. Her father, in his early 70s, has endured years of misdiagnosis which lead to complicated heart surgery last year that nearly took his life at the age of 71. Her daughter age 12, currently treated with ICD and medication. For years, many family members were misdiagnosed or treated inappropriately, until they received care at a center of excellence and are all doing well today.

It took a cardiologist that knew about HCM to help Lisa and her family. Thanks to genotyping, her family members now know who among them carries the gene. She wants to make cardiologists with training in HCM available to everyone so that no family suffers such losses.

Her family’s history of HCM is not that uncommon. There are thousand of families in the US living with HCM. Creating more Centers will ensure that patients with HCM live long and happy lives.

Sustainability

What are your two main challenges to finance the growth of your initiative

The HCMA does not need a great deal of financial support to scale up operations; therefore, there is only one financial challenge to describe, not two. It is a relatively young organization. Awareness of HCM is building and with it a strong donor base. Since approximately 80 percent of the funds to support HCMA come from private donations, it will continue to increase its fundraising program by creating new fund streams.

The main challenge is to launch at least two new HCM Centers of Excellence per year over the next 10 years. The cost for the HCMA to develop a Center is relatively minimal at $30,000 per location. The only direct costs are staff time, marketing, and producing and distributing patient education materials. Hiring more staff members will expedite the number of Centers developed per year.

The overall costs to the healthcare institutions that must commit funds to support the development of the Center. They have their own resources for fundraising that do not impinge on those raised by the HCMA.
How did you hear about this contest and what is your main incentive to participate?

HCMA is a recipient of an annual grant through Medtronic Foundation's patient link program. A representative from the Foundation contacted all grant recipients and alerted them to this contest.

The Story

Do you have an annual financial statement?

Yes. The HCMA has an annual financial statement.

Do you currently have an annual financial statement that tracks profit/loss?

Yes. The HCMA has an annual financial statement that tracks profit and loss.

Please describe the amount (and/or type) of funding you need to implement your initiative, at year 1 and at year 5.

All of the funding outlined above is the actual amount that the HCMA will raise annually to support the creation of the new Centers. In Year 1, it will need to raise $140,000 in additional funds as well as in Year 5 by raising an additional $180,000.

HCMA will increase its fundraising efforts as described above. It will create new funding streams to attract potential donors and increase the amounts provided by existing donors. Fundraising vehicles will include special events, annual direct mail appeal, online fundraising, grantseeking, and memorials.

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