

Creating Bridges for Cleft Patients

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Akanksha Sharma
Biology & Biotechnology '08
Date: May 5, 2006

Abhilash Nair
Electrical & Computer Engineering '08
Date: May 5, 2006

Kurtis Allain
Biology & Biotechnology '07
Date: May 5, 2006

Professor Jill Rulfs
Advisor

ABSTRACT

Cleft lip and cleft palate are widespread deformities in developing countries. Although many voluntary medical expeditions focused on cleft treatment are dispatched to these countries annually, no public database providing specific details of these trips exists. Forty-eight craniofacial surgeons in twelve north-eastern states were contacted to collect information regarding their trips. Twenty-three surgeons responded, nine of whom participated in such expeditions. This information is part of a website designed to facilitate connections between afflicted patients and specialists in this field.

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INTRODUCTION

The craniofacial region, referring to the face and skull, is the main center of nervous input from the senses of the body: sight, hearing, taste, and smell. This region is responsible for the ability to breathe, chew and swallow. A deformity in this region occurs when a facial bone, lip or palate becomes dislocated, is ill-positioned or is simply underdeveloped. This is the result of congenital problems that lead to a cascade effect affecting nearby tissues and bones and causing facial abnormalities ranging from mild to severe in condition. A large fraction of these deformities constitute cleft problems, namely cleft lip (CL) and cleft palate (CP). Cleft abnormalities appear as a hole either in the lip when the two sides of the lip fail to fuse together or in the palate when the two plates do not fuse during fetal development. Both cleft lip and palate may be present at the same time or independent of one another. (“Surgery,” 2006)

One in every 750 births in the US is affected by cleft lip and/or palate (CL/P) each year, resulting in 4300 affected newborns a year. CP without CL is the fifth most frequent congenital malformation with a rate of occurrence of 1 in every 2500 live births. These statistics vary among ethnic groups. Populations of Native American, South American and Asian descent are more likely to be affected by CL/P. In Native American populations, 1 in every 278 newborns is affected, compared to 1 in 750 newborns of European descent. In African Americans, however, the incidence rate is very low. (Berkowitz, 1994)

CAUSES:

The causes of CL/P have been explored by researchers for decades and are still under investigation. It is understood that it first presents itself during fetal development, where a deformity occurs when the growth of the facial skeleton is disturbed (“Cleft”, 2002). According to Dr. JL at the University of Massachusetts Memorial Medical Center, CL/P results from a genetic mutation, although the exact location of this mutation is still under investigation (L, 2006). It is widely accepted that Asian, Native American and South American populations have the highest incidence rate. Since CL/P occurrence is very rare in the African population (considered to be the oldest population) we can infer that “it had to mutate somewhere” at a later stage in human evolution (Lalikos, 2006). However, more research is needed to study the incidence and risk of CL/P development “among the various groups that exhibit different epidemiologic behavior for each race” (Vanderas, 1987; “Global,” 4).

Migration studies have also been conducted which indicate that population genetics may be used to understand the high incidence of CL/P in Asia and the South American countries. Populations that migrated to the Americas originated from Asia; therefore, there may be a connection between the Asian populations, the Native Americans and the communities of the various South American countries all of which report high incidence rates of CL/P. (Lemonick, 2006). This might suggest a genetic predisposition for CL/P that has survived over generations in these races. In regions where the European race has intermixed with these high-risk populations, CL/P rates tend to be noticeably lower. The exact nature of this genetic predisposition has not yet been identified, indicating that a series of linked mutations are probably responsible for the

phenotype. Currently, researchers are focusing on tracking CL/P incidence in multiple family trees around the world in an attempt to pinpoint potential genetic links that will enable us to draw a clearer picture of the abnormality at this level. (Brace et. al, 2001)

Another factor being investigated is the relationship between dietary patterns and the prevalence of craniofacial abnormalities. In rural parts of Africa, Asia, Latin America and Oceania, one or two staple cereal foods constitute the main source of food. In India and China, rice is a dominant and important staple food. Wheat in North America, maize in Latin America, and starchy roots in Africa complete the list. The staple food in these countries is cheap and plentiful, which allows even the poorest of people in these regions to consume them. As countries develop economically, consumption of the dominant staple food decreases. The fall in the consumption of foods of plant origin gets replaced by more meat and dairy products including chicken, eggs and cheese. This increase in meat and other sources of protein causes the diet to be increasingly well-balanced. Research shows that a well-balanced diet helps guard against diseases and reduces the occurrences of congenital problems. (“Role,” 43)

Abuse to the fetus, such as alcohol consumption, smoke inhalation, poor diet or a hormonal imbalance during pregnancy, also increases the chances of the deformity (Khoury et al, 1987; Munger et al, 1996). Some medications, such as the anti-seizure medicine *Dilantin* have also been observed to fractionally increase the CL/P occurrence rate (Abrishamchian et al, 1994). Environmental factors were studied in Hungary, where it was determined that children born to mothers who suffered from influenza, the common cold, orofacial herpes or gastroenteritis were at a higher risk to be born with an isolated cleft lip (Metneki et al, 2005). In addition, research has also shown that a

deficiency in folic acid has been linked to an increased risk of orofacial clefts in offspring. Intake of additional vitamins has been found to reduce these odds (Shaw et al, 1995). Any of these factors, alone or combined, can affect the fetus during the critical first trimester, which lasts from the 3rd to 12th week of pregnancy, and can result in the development of CL/P deformity (Cleft, 2002).

CONSEQUENCES:

A child born with a cleft lip or palate is not just a victim of social stigma and resulting self-esteem issues, but also of various physical problems. It is difficult to eat or drink because the absence of a barrier between the mouth and nose results in liquids entering and exiting from the nasal passages. A CP afflicted baby might adapt and learn swallowing techniques as a survival strategy, but this is not simple and must continually change as the child develops (Sykes et al, 1999; Richard, 1994). Without treatment, namely surgery, to correct for the CL/P condition, these eating concerns can become a critical problem, lack of nutrition can affect the growth and weight of the child (Lee et al, 1997; Avedian and Ruberg, 1980).

Eustachian tube dysfunction is a complication that almost all cleft palate patients suffer from, “resulting in chronic ear disease and hearing loss” (Smith et al, 1994). Speech is hindered because the air blown out of the nose affects diction. Children with cleft palate might progress in language, but will do so at a much slower rate and exhibit “more errors overall [as compared] to their non-cleft peers in their phonological process” (Chapman et al, 1992). Dental problems may also result from CL/P, causing the bleeding of gums, along with chipped and/or corroded teeth (Vichi and Franchi, 1995). These and

other problems affect the lives of thousands of afflicted children and their families in the United States alone, and the prevalence of this disorder is increasing in developing countries, where proper medicinal help and quality care are scarce. (Deutsch, 2005)

Across the world, the social stigma attached to the deformity is tremendous. In certain countries, such as India or China, a child born with CL/P is considered to be a symbol of evil or bad luck, and will most likely be abandoned by the family and community. Without treatment, the afflicted individual will carry the burden of his/her appearance through life; it can affect education, social status, and marriage. Self-esteem and confidence are severely diminished by the sense of being physically abnormal (de Andrade and Angerami, 2001; Broder et al, 1994). Even if CL/P is not life threatening, it severely affects the child's ability to live a full life (ASPS/PSEF, 2005).

TREATMENT:

The American Cleft Palate Association (ACPA) maintains standards of treatment for CL/P in terms of the patient age, time of recovery, etc. Cleft lip operations are generally performed when the infant is 8 to 10 weeks old. In this surgery, the outer portion of the cleft is turned down, and the muscle and skin of the lips are pulled together ("Surgery", 2002). Since it is a straightforward frontal operation, the child is usually able to go home the same day (L, 2006). Though the procedure is simple, parents are made aware of several potential complications, such as excessive bleeding and infection with scar tissue. The majority of the time, there are no complications that might require constant care or extended hospital stays. (Deutsch, 2005)

Cleft palate surgeries are normally performed at 10 months. The palate of the mouth is essentially rebuilt by joining the muscle of the two sides together while allowing for the proper amount of flexibility and stretch necessary for speech or eating (“Surgery,” 2002). The surgery is unique from person to person depending on how large the affected area is, thus the type and number of procedures and recovery time vary from case to case. After CP surgery, the child maybe held overnight to monitor the child’s stability. Since the surgery is performed inside the mouth, a possible complication is that swelling or sudden bleeding of the palate might obstruct the airway. Thus, oxygen levels are constantly checked and the child is released the following day if he/she presents as stable. The CP surgery is much more painful than a CL surgery; fortunately it heals quickly. (Cleft Lip, 2005)

If the gum line has been affected in any of these surgeries, an additional bone graft may be required. Orthodontic work is usually needed at various stages of the facial development to ensure the proper shape of the jaw and positioning of the teeth (Berkowitz, 1994). These procedures are performed at varying ages corresponding to the growth of the child, and follow-up operations are done as needed in between surgeries (Bone, 2005). Often the entire process is quite lengthy and spans several years; “...if there’s both a CL and a CP repair, then we tell the parents they’re looking at around 12 surgeries up until the age of 17,” states Dr. JL.

Depending on the recovery and needs of their child, speech therapy may also be sought by parents. Since the CP surgery is performed at 10 months, when the child has not yet started speaking, parents can wait a year and observe the child’s ‘babbling,’ and once he/she is able to form words, carefully listen to the sound and formation. Speech

therapy is considered if modality or nasality seems abnormal. The doctor then evaluates the needs of the child and refers the family to an appropriate therapist. (“Speech”, 2005)

Other problems may occur, such as a hole in the palate caused during a follow-up surgery or as a result of palate expansion during orthodontic work, but this is treatable and is not permanently damaging (Berkowitz, 1994). Scar tissue might be both cosmetically and functionally problematic but with an experienced surgeon, its presence can be significantly minimized. In Dr. JL’s experience, patients with the highest incidence of “clefting” (i.e., the Asian and Hispanic populations) usually experience more problems with their scars such as excessive thickness or contracted scars. Generally the scar is not overly apparent, depending on the skill of the surgeon, and is known to fade over time. Scar cream and massaging the area surrounding the scar tissue is recommended to all parents, but surgeons are especially aggressive with families from these “clefting” races to make sure extra care is taken to ensure minimal scarring. (L, 2006)

FINANCIAL RESPONSIBILITY & INSURANCE

In the United States, the cost of CL/P treatments can total almost a quarter of a million dollars. This includes various hospital fees that range from billing to in-patient care, to the high charges of the surgical team, not to mention the cost of drugs needed post-surgery. Thus, to be able to afford treatment, Americans need some form of assistance. Support is given by way of managed care or insurance companies, and public assistance programs can help low income families. It is important for a family with an afflicted child to become well aware and educated of their insurance coverage options.

Insurance companies and Medicaid generally will not cover cosmetic work unless there is a functional need for it, meaning that the abnormality affects the body physically in a detrimental and potentially harmful manner. The Treatment of Children's Deformities Act (HR 49/S 1822) requires insurance companies to cover reconstructive surgical procedures if they are needed to improve the “function of abnormal body structures, or restore those body structures to a more normal appearance.” Since there is often a fine line between what can be classified as a functional versus a cosmetic need, problems with insurance companies can occur with both the initial surgery as well as the ‘touch up’ or follow up surgeries that are often greatly needed as the child grows and reaches adolescence. Often, the process for receiving coverage is complicated and time-consuming, where families and doctors must prove the surgery’s necessity through photographs and detailed explanations from the surgeon. (DesOrmeaux, 2003)

This same fact applies to extensive speech therapy. Once the child enters school, a form of therapy is available from the school district, but it is not as specialized as a CL/P afflicted child might need. These children are usually able to speak and be understood without many problems, but there is an over nasality to their voice, resultant from the hole in the palate, which needs the proper care and attention. This hyper-nasality or hyper-resonance is best treated by speech pathologists trained to understand these modalities, as they can best evaluate the child for the kind of help he/she might need. This might result in another surgery required to properly close the opening at the back of the nose (the velopharyngeal port), prescription of a palatal life appliance to elevate the soft palate and decrease valve space, and even intensive articulation therapy with a speech bulb appliance to stimulate muscle wall movement (Berkowitz, 1994). Such

evaluation cannot be provided with a school speech therapist who is usually not trained in providing such extensive care. To get coverage for this ‘advanced’ therapy requires persuasion from the doctors regarding the need for the process and its consequences, though this may not even be enough to guarantee full coverage (L, 2006).

Families face the highest bills when it comes to orthodontic or dental work. Most parents will save up for this stage, since it is rare that insurance companies will allow for this dental cosmetic work to receive full coverage under the policy. This is again because restructuring of the teeth or the jaw may not be a functional necessity. If a family is covered under managed care, the situation becomes especially difficult at this point. (“Dealing”, 2005)

Medicaid differs in the reimbursement amounts it provides to surgeons or dentists, which are quite low when compared to the rates paid by most insurance companies. For instance, according to the Massachusetts Division that administers Medicaid, dentists are typically reimbursed only 45% of their fees for Medicaid patients (Ring, 1999). In fact, the United States is currently experiencing a national problem with orthodontists and dentists in private practice refusing to accept Medicaid from patients. For instance, almost 85% of the 6500 dentists in the state of Michigan have refused to accept Medicaid, there are very few providers in Delaware, and dentists in Indiana are refusing to take on new patients who are on Medicaid (Ashbridge, 2005; Boen, 2006; “Fewer,” 2006). According to one article, the American Dental Association stated that only “one in four children [covered by Medicaid] gets an annual dental check-up” (Boen, 2006). Doctors that refuse care realize it is more profitable to perform the work *pro bono* than accept Medicaid because they are “reimbursed far less than the cost of running [their]

office to treat [patients]” (Ring, 1999). This means that fewer orthodontists/dentists in the United States will accept Medicaid with the exception of those who work in public institutions that require them to do so. Thus, these families must search hard for the treatment they need. Some dentists and orthodontists are known to take up a limited number of cases each year without charge, and accept patients into this quota through referrals from a local surgeon (L, 2006).

SITUATION IN DEVELOPING COUNTRIES

Much research has been, and continues to be conducted in order to investigate the reasons behind the higher incidence of cleft lip/palate (CL/P) in certain regions over others or their prevalence in communities of certain ethnic backgrounds. Most of these regions are located in South America, Asia – Far East, and Oceania, and are termed by the United Nations as developing or ‘least developed nations’. Such countries are characterized by a low standard of living, a low GDP (Gross Domestic Product) and a moderate to low Human Development Index (HDI) (“Human,” 2005).

HDI is a quantitative measurement that the United Nations uses in order to compare one country to another on several aspects of human development. These include life expectancy, literacy rates, GDP (Growth Domestic Product) per capita, and the percentage of a country’s labor force that works in the primary, secondary, and tertiary sectors. Though HDI by itself is not enough to measure a country’s development rate, the UN has used it as a gauge to categorize countries. A country with an HDI of 0.8 or more is highly developed and an HDI between 0.5 and 0.8 is considered moderately developed. Any country with an HDI below 0.5 may be considered to be a least developed or

developing nation (“Human,” 2005). The United Nations uses a combination of different factors and methods apart from the HDI to characterize different countries, but these can vary greatly. The UN states that “In common practice, Japan in Asia, Canada and the United States in North America, Australia and New Zealand in Oceania, and Europe are considered developed regions or areas” (United, 2006).

The characterization of ‘developed countries’ becomes especially important where health and disease is considered. The health system of a country will be affected by its economic resources, which dictate its ability to maintain hygienic environments and provide public care systems or subsidized medical care to the population that needs it. A high incidence of disease has been reported by governments who are unable to ensure that a large part of its population is living in sanitary conditions and that proper health care is available when and as needed (“Human,” 2005). The number of individuals that are affected if the disease is contagious, such as cholera or typhus, and the fatalities reported rises dramatically in a country where the situation cannot be controlled by health officials, versus a “developed” country like the United States where treatment and care are seen as widely available. Consequently, treatment in these countries is not as widespread or as efficient as needed to curb the problem or help those afflicted by a number of different medical conditions. These treatments may include medicines, fluids, or surgical procedures, depending upon the situation.

CL/P afflicted children are affected in the same way in such countries, regardless of the fact that it is not an infectious disease but a congenital deformity. Deficiencies in the health care system, which include low investments by both public and private sectors, obsolete and unusable equipment in public hospitals, low availability of medicines in

public health facilities, and dilapidated states of buildings result in surgical treatment for these patients being compromised or even unavailable (Sharma, 2005). Often proper care is available in private hospitals but the high costs can only be afforded by the higher income sector. Families with limited income must make attempts at receiving social assistance, if such a program is available, or await a mission trip from an overseas medical trip (Silverman, 2006). Aside from this treatment, general health education of the risks and precautions to be taken during pregnancy is not available. Young mothers might not be well educated on the harmful effects of smoke or alcohol, or might not take care during the critical first trimester to keep their fetus safe from developmental damage. Maternal health and diet, though they are not isolated factors, do affect the chances of a child being born with a deformity, which includes CL/P.

In recent years, annual trips to such countries by various surgeons and non-profit organizations from the United States has not only provided medical services to these patients, but has done so in a manner that drastically reduces the financial obligation to these families. Instead of having to pay for the surgery in full, the patients need only pay for the supplies as well as the cost of their own transportation to and living expenses in the city where treatment is provided. (Silverman, 2006)

OVERSEAS MEDICAL TRIPS

An interview with Dr Rick Silverman, previously a plastic and reconstructive surgeon at the University of Massachusetts Memorial Hospital and currently in private practice, shed more light into the various aspects of overseas mission trips like the ones he organizes. Dr. Silverman, who has been involved with these trips for over 15 years,

takes teams of 26-28 medical professionals and volunteers to Latacunga in Ecuador for the first full week in February. In the week they spend there, they attend to between 200-250 people and perform 90-100 surgeries, starting with their initial clinic on Sunday and ending the following Saturday. Members of the local chapter of the Rotary club in the city of Latacunga make arrangements at the hospital to ensure that the news reaches the surrounding cities and villages. Families travel as many as 10-15 hours to get to the week-long clinic. There is a loose pre-screening process, limited to announcing that 'only patients with congenital problems or deformities of a plastic surgery nature should come' and people with varied medical problems are drawn into the first clinic. The surgeons are often forced to turn away most of the crowd as they try to limit their resources and time to CL/P patients and an occasional hand or ear reconstruction. This year, for instance, they only accepted 98 of the 250 cases present in the initial clinic. (Silverman, 2006)

In another village, Puyo, to which Dr. Silverman travels later in the year, a stricter protocol must be used to determine eligible patients, since they must then travel by boat or plane to the city. A medical professional from the local hospital is present to evaluate these patients and screen their problems before they reach the team. Once the team departs, any follow up, which is usually reduced to a minimum, is the responsibility of the director of the clinic where the surgeries will be performed, and of physicians that are present in the area. Efforts are made to ensure that recovery is quick and comfortable, so that patients are not forced to stay in the hospital past the week itself. If the surgery takes several stages, such as ear surgeries, it is planned over years, one stage completed each subsequent year. (Silverman, 2006)

Most teams like Dr Silverman's consist of anesthesiologists, nurses, surgeons trained in the various specialties, in this case, CL/P, hand surgery, plastic and general surgery residents, speech therapists and volunteers. Teams may be big or small depending on the organization or the preference of the team leader. For instance, Dr. Rothkopf, another surgeon at UMass, prefers his teams to be small, between 6-10 people.

Depending on the number of people traveling, the entire effort can become quite expensive, ranging from \$900-\$1200 per head. Individuals are expected to pay their own airfare and living accommodations (usually a little over \$1000), though the team leader might make efforts to sponsor nurses. Funds are raised for these 'private' trips through friends, families, and sometimes local churches or other charitable and philanthropic organizations. Supplies are collected by donation, with participants salvaging surgical instruments, medicines and other needed materials, through efforts that are initiated months in advance in hospitals like UMass or the St. Ives Hospital in Boston, MA. As the trip draws near, the supplies collected are packed. Fluids or narcotics are bought more conveniently in Ecuador, where the prices also tend to be lower for these items.

(Silverman, 2006)

One important aspect of any overseas trip is the language barrier that must be crossed, especially in a doctor-patient relationship. It is absolutely necessary that both sides are able to communicate and understand one another with ease. A basic knowledge of the language is often required when traveling with such teams, even if a medical interpreter is present. For instance, most members of Dr. Silverman's team are fluent in Spanish, and the others have a rudimentary knowledge of the language. (Silverman, 2006)

Apart from how the trip is funded in the United States, it is also important to note how the cost is supported on the other end. In most cases the patients do not pay for the services, but in certain places donations are accepted if the family can afford to pay some amount. Donations such as these support clinics like the Fundacione Tierra de Nueva in Quito, which is run by a plastic surgeon who hosts trips such as Dr Silverman's almost once a month at a comfortable, well-equipped facility. In other places, families might need to cover living expenses, or provide medicines for their child. The service received in either case is invaluable and often something that would not have been financially possible otherwise. Though these surgeries cost only \$300 at a local facility through a local surgeon in Ecuador, it is still a significant amount for the large proportion of low-income households. (Silverman, 2006)

Large, established organizations like Smile Train, Interplast or the Medical Missions For Children (MMFC) lead trips that are sponsored by large corporations or businesses (such as airlines, medical supply companies, etc) and thus have more access to a large number of resources. Their work is not as limited as independent trips or trips that go through local clinics or hospitals tend to be, which means several ongoing efforts or frequent trips across the world are possible. Usually, trips led by these organizations are run in a very different manner than the trip that has been described above. For example, surgeons and nurses may volunteer for organizations like Interplast and MMFC to join trips to a particular place. The entire trip is planned and arranged by the organization and the surgeon just supports him/her self monetarily: all other preparations are completed by the sponsor.

RESOURCES

Smile Train is a non-profit organization which focuses on providing financial empowerment to surgeons or local medical teams in developing countries. Educating medical professionals in developing countries is an important goal, behind which lies the theory that once the tools are provided, local clinics and hospitals can themselves begin to handle CL/P cases. With the support of “the world’s leading cleft organizations and medical institutions”, services are provided to patients in almost 55 countries, including the US. These services include free surgery, free education and training for medical professionals, and support for research projects in the CL/P field (Smile Train, 2006). In fact, Smile Train provides access to the world’s largest database on cleft surgery for medical professionals and the public through its online cleft library; other agencies carry out similar work. Along with sending medical teams overseas, Interplast’s plans include efforts similar to Smile Train’s work. CleftLine, or the American Cleft Palate Association-Cleft Palate Foundation (ACPA-CPF) provides hotlines that can help patients and families gain education through publications, information about the disease, and contacts to local craniofacial teams and support groups in the US.

Apart from questions about financial resources and education, another issue that parents in the United States face is how to select a surgeon for their child. With the exception of a track record, there are no particular qualifications that a parent of a CL/P child can look for to identify an especially capable surgeon. Surgeons may have backgrounds in plastic surgery, ENT surgery, or even oral surgery. However, they should have had some experience in CL/P repair work, either through a pediatric plastic surgery fellowship or through craniofacial fellowships. It must be noted that the established

leaders of the field usually do not have such experience because these fellowships did not come into existence until recently. Families could do better by looking at past cases treated by the surgeon. Before and after pictures might not be directly available because of privacy and consent issues, but often surgeons give parents the options of contacting a previous patient directly. This family can then choose to share their story and provide an idea of the surgeon's track record and ability.

The American Cleft Palate Association and other non-profit organizations such as CleftLine and Smile Train sponsor or support hundreds of clinics around the world. Each of these organizations maintains databases of the clinics and medical expeditions they support. However, while contact information is given, details of each trip including dates and locations are usually not provided. These particulars can be far more important than contact information to a patient or a family member who lives outside the United States and cannot easily afford the phone call to the doctor.

Our initial exploration confirmed the fact that a detailed compilation of craniofacial clinics and their medical expeditions would be a valuable resource to various patients and medical professionals, not only in the United States, but in various countries that benefit from these trips. The goal of this project was to design a website that facilitates contact between CL/P afflicted patients around the world and specialists from the US and also to identify a host for such a resource. This would allow for ongoing support for volunteer expeditions that provide treatment and access of information from these trips for both patients and members of the craniofacial surgical field.

MATERIALS AND METHODS

WEBSITE DESIGN

The website was designed to provide a source of information to families living in under-privileged countries about resources for treatment of CL/P. The blueprint and design of our website included the following sections initially.

- an introduction to the purpose and goals of the project
- an annual calendar that displays the various trips in a chronological order
- a list of the annual trips organized by the states from which they will be leaving, based on the responses we received to the emails.

Over the course of the project, more information was collected and this initial plan was expanded to include ideas that contributed to the intended purpose. The website at its current stage is available in screenshots as part of the results. It is currently addressed towards CL/P patients and their families, medical professionals who participate or organize such trips, organizations that specialize in providing CL/P resources, social service agencies around the world, and other hosts for trips that leave the US.

Links distinctly show families what group or organization will be traveling and to what part of the world. The website also allows members in the craniofacial field to learn about, contact and join a pre-existing and pre-organized effort. To avoid any liability issues we have posted only that information for which we have received permission. A fabricated example of the kind of information we initially set out to look for is given below.

An organization, Childsmile - based in New Hampshire, is receiving sponsorship from Smile Train. Each year a team of 10 surgeons and nurses travel to Indonesia to

perform various cleft operations. Our website would be an ideal location to post information regarding this medical expedition in the following manner:

- *Name of institution: Childsmile*
- *Contact information for doctors traveling with their specialties--Team leader name, address, e-mail address, website (if any), telephone number*
- *Dates and duration: March 5-10, 2006*
- *Specific location: Hospital Name, Jakarta, Indonesia*
- *Medical procedures involved: Pediatric Cleft Palate surgeries*
- *Local contact in Jakarta: Name, address, e-mail address, website (if any), telephone number*
- *Contact to make donations: Mr. C, (555)-555-5555*

INFORMATION GATHERING

Based on this plan and initial research on the organizations, the search commenced for craniofacial surgeons working in hospitals, private practices and local clinics in individual states. Since a prototype was being developed for what would be a much larger and more comprehensive resource, it was decided to limit information gathering to the north-eastern area. This search was initiated using websites of CL/P resource organizations that provided the contact addresses of these doctors to the public. Smile Train, CleftLine (Cleft Palate Foundation), the American Society of Plastic Surgeons (ASPS), the American Cleft Palate Association, Widesmiles, and FACES, The National Craniofacial Association, are all websites open to the public that list CL/P specialists by state. Through information mining on all sites, a comprehensive list of

contact information for forty-eight surgeons in twelve states in the north eastern United States was obtained. Next, a template e-mail was sent to the contacts, based upon obtaining the above information. This e-mail has been provided as Figure 1.

The initial email concept was to include the names of Dr JL and Dr RD, both of whom are involved in such activities and are affiliated with an academic medical center, as a way to authenticate our project. However, this led to several legal obstacles. Firstly, the e-mail posed a liability issue to the doctors, who, as a part of a public institution, were required to obtain necessary legal waivers from the institution. Without such permission, they could not accept sponsorship of and responsibility for the project. The process to achieve this consent can take up to three months. This would have delayed progress and so alternative strategies were investigated.

Dr. JL referred the team to Dr. Richard Silverman, who works as an independent practitioner, in Newton, MA, for further guidance. Dr Silverman is a plastic and reconstructive surgeon, who has himself organized annual trips to Ecuador for the past 15 years. He displayed enthusiasm for the work at hand and was willing to allow us to use his name for authentication purposes.

Email letters were dispatched which included the names and contact information of Dr. Silverman and the WPI team advisor, Prof. Jill Rulfs, to forty-eight craniofacial surgeons from the following states in the North East region: New York, Maine, Massachusetts, Pennsylvania, New Hampshire, Vermont, Delaware, District of Columbia, Maryland, Rhode Island, Connecticut and New Jersey. The letter was sent to all contacts as a general introduction of the project and its purpose, and to request their participation by sending back information on all medical trips in which they were

involved that focused on providing craniofacial surgical services at their destination. One week was given for replies from these places.

The next approach was to call these hospitals and clinics to follow up on the e-mail and directly discuss the project with these individuals. It was hoped that this strategy would allow for the opportunity to clarify the various aspects of the project in case the doctors were hesitant to divulge their information. Contact was mainly with the secretaries of these surgeons, but in some cases the team spoke directly to the doctors as well.

OBTAINING A WEBSITE SPONSOR

From the outset, we recognized the need for a credible organization to host the website. Dr. JL referred us to Ms. NS of the American Cleft Palate-Craniofacial Association since the ACPA seemed the ideal organization to host this website. The ACPA is a well established organization and is visited by many families and medical professionals who are in search of information regarding cleft lip and palate. The greater the number of people who access the site, the more effective it could become.

The initial contact with ACPA was made by Dr. JL, who directly presented the project proposal (attached as Figure 2). The proposal was run through the majority of the appropriate committee chairs and council members at the ACPA, after which Ms. NS informed the team that the committees' comments would be collated and presented at the Executive Council Meeting on April 2nd. Dr. JL informed the team that she too would be attending this committee meeting to support our proposal.

Figure 1: Letter to Initial Contacts

Dear _____,

We obtained your contact information from the following website ----- focusing on providing information to patients and families dealing with cleft abnormalities.

We are three students studying at Worcester Polytechnic Institute (WPI) in Worcester, Mass. Every student that attends WPI has to complete a series of projects that shows growth in a particular area. The Interactive Qualifying Project (IQP) joins groups of students from varying disciplines to address a problem that lies within the boundaries of science, technology, social structure and human needs. The purpose of the project is for WPI graduates to understand how their field of work affects the society of which they are a member. We were interested in gearing this project towards the field of healthcare.

With the help of Dr. Rick Silverman, we are hoping to begin a project with the American Cleft Palate Association (ACPA) in which we are developing an easy to navigate web site of the various non profit and volunteer organizations in and around the Northeast coast that provide surgical services to foreign (or domestic) patients who need cleft

palate surgeries. We expressed our concern at the fact that there are a number of medical craniofacial expeditions that reach several developing countries but there is no organized web site to announce these services. The following information will be posted:

- Name of Institution
- Contact information of doctors traveling with their specialties
- Dates and duration
- Specific location
- Medical procedures involved
- Contact for Donations

Families that wish to be considered for future help or guidance in the United States can then bring patients to these places to be diagnosed in person by a specialist. There will no costs or liability involved for hospitals, clinics or individuals that wish to announce their trips.

If _____ is planning any medical trips in the plastic surgery area, to any part of the world, we would like to include that on our site.

If you would like to verify our project's authenticity, you may contact Dr. Jill Rulfs, PhD, Associate Professor at WPI (jrulfs@wpi.edu) or Dr. Rick

Silverman, MD, from the Caritas Plastic Surgery Clinic in
Newton, MA (litlr iki@aol.com).

If you prefer to speak with us please give the number
to reach you and convenient times for you. If you would
like to contact us, our number is _____.

We look forward to hearing from you.

Thank you so much for your time.

Sincerely,

Kurtis Allain kallain@wpi.edu

Abhilash Nair abhilash@wpi.edu

Akanksha Sharma aksharma@wpi.edu

Figure 2: Project Proposal to the ACPA

Dear Ms. NS,

We are three students studying at Worcester Polytechnic Institute (WPI) in Worcester, Mass. Every student that attends WPI has to complete a series of projects that shows growth in a particular area. The Interactive Qualifying Project (IQP) joins groups of students from varying disciplines to address a problem that lies within the boundaries of science, technology, social structure and human needs. The purpose of the project is for WPI graduates to understand how their field of work affects the society of which they are a member. We were interested in gearing this project towards the field of healthcare.

Our advisor at WPI is Prof Jill Rulfs, Associate Professor in the Biotechnology Dept here. She directed us to two surgeons at the University of Massachusetts Medical Center, Dr. JL and Dr. RD with whom we met in early December. In this meeting, we discussed the possibility of working with the American Cleft Palate Association to develop an easy to navigate web site of the various non profit and volunteer organizations in and around Massachusetts (and other states) that provide surgical

services to foreign (or domestic) patients who need cleft palate surgeries. We expressed our concern at the fact that there are a number of medical expeditions (including the twice-a-year Ecuador trip with UMass plastic surgeons) that reach several developing countries but there is no organized web site to announce these services. The webpage we create will be under the ACPA wing which can be maintained and updated by the organization after the initial setup. Contact information of surgeons who wish to advertise their coming work in a particular place, along with dates, duration and location, and medical procedures emphasized will be posted at a regular basis. Families that wish to be considered for future help or guidance in the United States can then bring patients to these places to be diagnosed in person by a specialist.

If the ACPA is interested in supporting our project, we shall be conducting it (collecting information, setting up the website, etc) for the entirety of the spring semester, and a longer period if needed. There will be no cost to the ACPA, it will be a volunteer effort on our part entirely.

Based on our discussion with Dr. JL and Dr. RD, and our exploration of the ACPA website and other supported sites-CleftLine, and Smile Train-we created a general

example of information that we are looking to collect.

This is given below:

1. Say an organization Child Smile, a fictitious organization receiving sponsorship with Smile Train is based in Kentucky. Each year a team of 10 surgeons and nurses travel to one city in Indonesia (which varies from year to year) to perform cleft operations. This is usually in the springtime, in March.

Then, our website is ideally a posting place for Child Smile. They place the following info:

Dates: March 5-10, 2006

Place: City of ATX, Province D, Indonesia

Name of contact and other phone/email info

In addition, individuals who want to help sponsor the trip financially or want to accompany can contact.....

2. Dr XYZ in Mass performs cleft surgeries but he also specializes in lower limb cases. He will be coming to Indonesia with Child Smile. At the same time he is willing to look at patients who need his help or advice (i.e., a diagnosis or a prognosis). The information of his trip can be provided along with contact info for anyone who needs it.

We are still somewhat unsure of how wide we want to spread our efforts-restricted only to the New England area or spread across the US, since the ACPA is a national organization and the website should ideally serve a large number of people, but it might be difficult to organize all of that information in the time we have. We feel we can better understand the best course to take later in the course of the project once we know if it is indeed something the ACPA would be interested in, and after your views on our ideas. If you accept the project idea, we shall keep you updated along with Dr L at UMass at a regular basis, as desired. You may get in touch with us through this email: _____. If you would prefer speaking with us, the number to reach one of us is _____. We look forward to hearing from you.

Thank you so much for your time.

Sincerely,

Kurt Allain kallain@wpi.edu

Abhilash Nair abhilash@wpi.edu

Akanksha Sharma aksharma@wpi.edu

RESULTS

RESPONSE RATE

Of the forty-eight craniofacial surgeons contacted through e-mail, three replied within twenty-four hours. Of these three, only one was involved in any sort of overseas trips. The other two indicated that they did not participate in such endeavors. The team waited for responses from the remaining forty-five doctors for almost two weeks before further action was taken. After this period was over, follow-up phone calls were made to the forty-six surgeons that had not responded. The project was discussed with twenty three of these surgeons, and nine surgeons confirmed their participation in taking medical expeditions for craniofacial treatment.

The analysis of these results is as follows. Primary contact was established and within four weeks 100% of the doctors had been contacted at least once; the majority was contacted by both email and telephone. We only received a 6% response rate via e-mail but the follow-up attempt resulted in our being able to directly discuss the project with 47% of our contacts. Out of this 47%, 39% were able to give details of their trips—the remaining did not participate in overseas expeditions. For an additional 50% of the database, there is basic contact information. This fraction of the contacts thus remains inconclusive regarding participation in international trips since they did not respond to our emails or return phone messages we left. The remaining 3% includes doctors we could not reach at all either because the email address was invalid, or the telephone number was not in service any longer.

All of the data obtained through email and phone calls has been tabulated by state. These data includes the name of the institution, the name of the individual who

volunteered the information, locations and dates of trips, medical procedures performed and other contact information.

WEBSITE

The website has been designed using Macromedia Dreamweaver MX. Since the website is specifically geared towards the use by patients in developing countries, where internet access may be of variable quality, the website uses a simple interface that contains minimal graphics and media files. It uses forms to collect information from users and medical professionals. These forms have been built with the aid of *www.madaquad.com*. When users send their information through these forms, these forms are built securely enough that information is only sent to the webmaster through an e-mail. Since the website cannot currently be accessed from a permanent location, we have included some screenshots as Figures 3-17.

All the collected information has been entered into a Microsoft Access Database. This is the backbone of the website. This database contains all the details of the medical expeditions that leave for developing countries. The uses of a database are two-fold. First, it allows the webmaster and host organization of the site to easily add, remove or edit any entry or information from and into this database. Secondly, it allows the website to be more versatile, which results in a more user friendly environment for users to access.

Patients and families can browse through the site and look for information in two different manners. Future medical trips and expeditions are chronologically organized through a calendar (Figure 5). This calendar is organized by months and users can see the trips that are taken at a particular time-period of the year. The calendar needs to be kept

up-to-date by the host organization of the web site so that users can get the latest information regarding trips. Patients can also take advantage of a ‘regional search’ that is offered on the website (Figures 6-9). This allows patients to search for trips that arrive in their area from a particular state in the United States. This is a more user customizable option as visitors to this site can filter through many of the listings that are available to find the particular information they are looking for. Families may also access other resources on CL/P, such as links to the websites of ACPA or Smile Train, and this manuscript (Figure 10).

Apart from patients and families, the site is also designed to appeal to medical professionals. Unless the host organization can receive up-to-date information from medical professionals regarding their medical expeditions and trips to developing countries, the website’s information can become outdated very quickly. In order to rectify this problem, the website incorporates a simple-to-use form that allows doctors, surgeons, or anyone pertaining to the craniofacial field to send their information to the host organization quickly and easily (Figures 11-12). Once the medical professional submits his/her information, the data is sent via e-mail through the website to the host organization automatically. The webmaster of the site can then access this information and update the *Access* database by opening the file and entering the information that has been submitted. This simple procedure automatically adds the new information to the website’s information catalogue.

While it is imperative that detailed information about trips is shared with medical professionals, patients and their families, it is just as important that the site is able to share the impact that these trips have on the outside community to the common person.

These stories help the people not directly impacted by this disorder to understand the importance of such trips and may encourage them to donate money to fund such trips and increase the frequency of medical trips to developing countries. The website encourages this activity by asking patients and/or medical professional to submit their stories, experiences and memories relating to any moment of their craniofacial experience (Figures 13-14). Anyone visiting the website can send their stories to the host of the website through an in-built form. These stories can also be sent anonymously to hide the identity and privacy of a person.

Due to the complexity of this project, the website is in constant need of update, renewal and modification. As the team is constantly looking to improve the site, users are encouraged to send their thoughts, comments and/or feed back on both the physical look of the website as well as the content it holds. With the inclusion of a form on the website for this purpose, input from our visitors allows us to ascertain what additional features they would like the website to incorporate in the future (Figures 15-16).

This website is currently not online. As university students, the team cannot take the liability or responsibility of allowing this sensitive information to be viewable by the general public. It would also serve little purpose for this university to host the site, as its purpose would not be met. CL/P patients and families would not be properly directed to a site hosted by a technical university. However, if this site was hosted by a professional organization that relates directly to CL/P, whose website is visited by thousands of people every day, the outreach of our project would be significantly larger. Individuals looking for this information can look for it easily and conveniently on a site that they already frequent. Moreover, search engines such as Google and Yahoo would be more likely to

direct internet browsers to more well known and established CL/P websites. Finally, the responsibility of hosting such information would belong to the organization that already hosts such kind of information and if not, then has the ability to obtain these rights from the clinics and hospitals directly. They would also have a large database of information from which they can add to the online search tools.

WEBSITE SCREENSHOTS

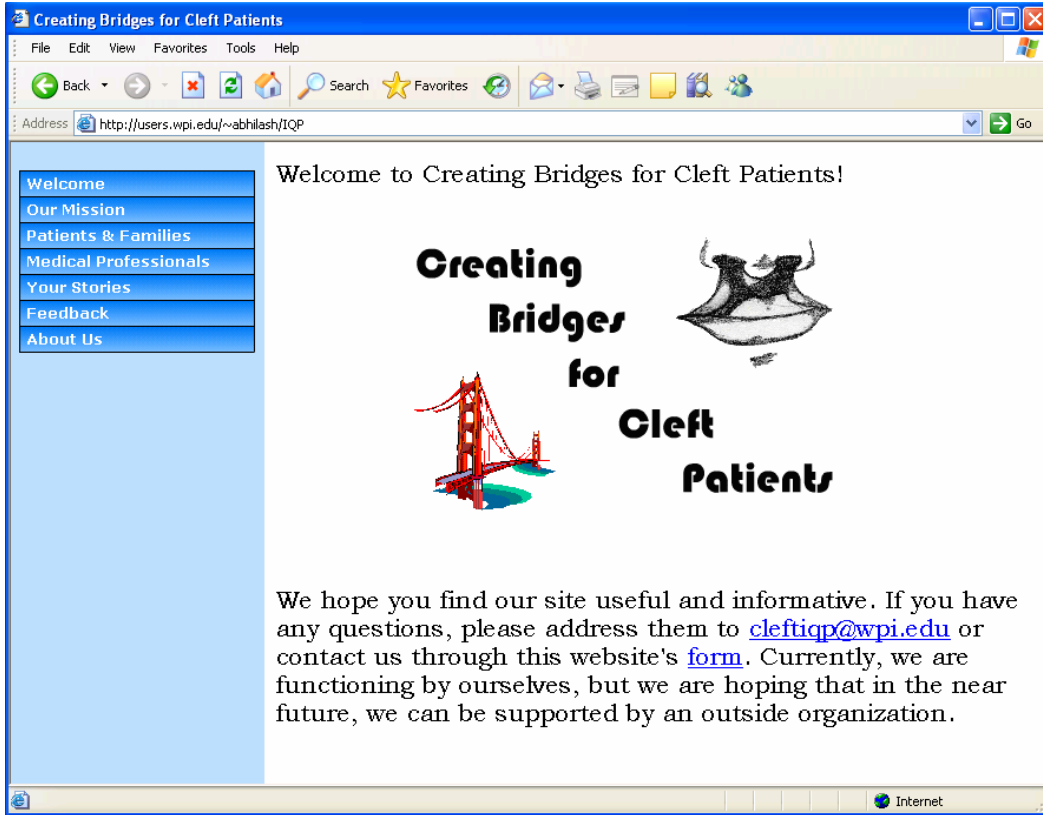


Figure 3: Homepage

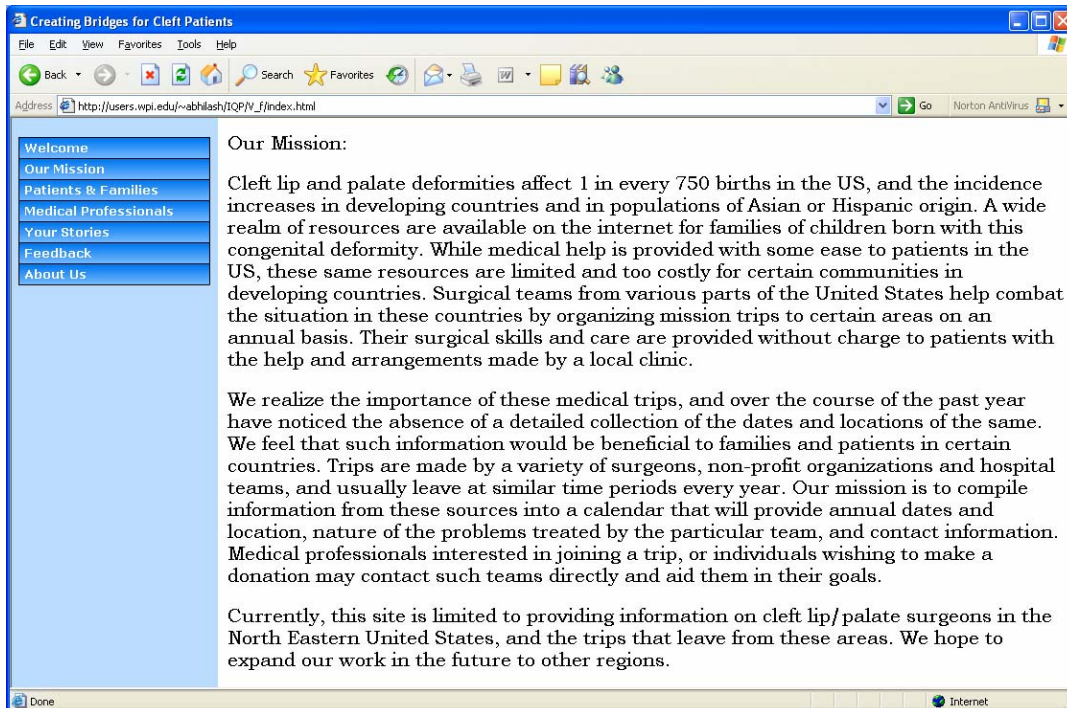


Figure 4: Our Mission

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
26	27	28	March 1	2	3	4
			Shriners Hospital for Children to Vietnam, 6 days			
			Vindoray Shah, MD to India, 4 days			
5	6	7	8	9	10	11
Shriners Hospital for Children to Vietnam, 6 days						
Vindoray Shah, MD to India, 4 days						
12	13	14	15	16	17	18
19	20	21	22	23	24	25
			Children's Hospital of Philadelphia to Poland, 8 days			
26	27	28	29	30	31	April 1
Children's Hospital of Philadelphia to Poland, 8 days						
2	3	4	5	6	7	8

Figure 5: Annual Calendar

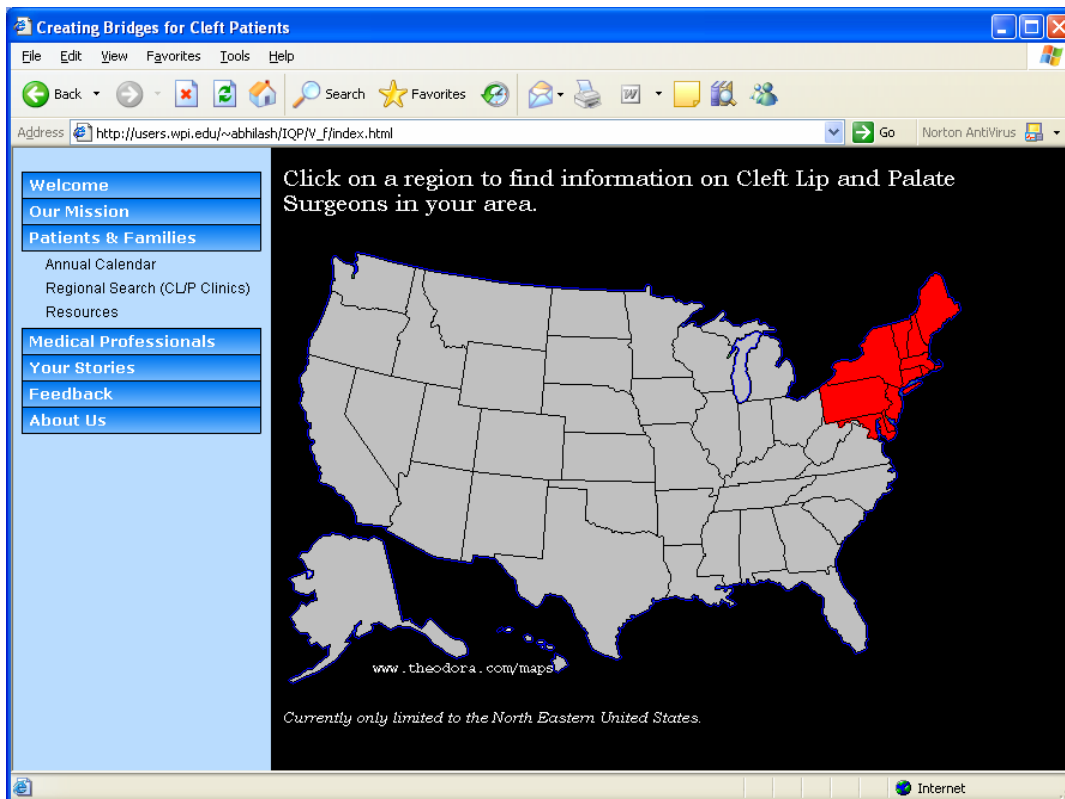


Figure 6: CL/P Search for Surgeons in the US

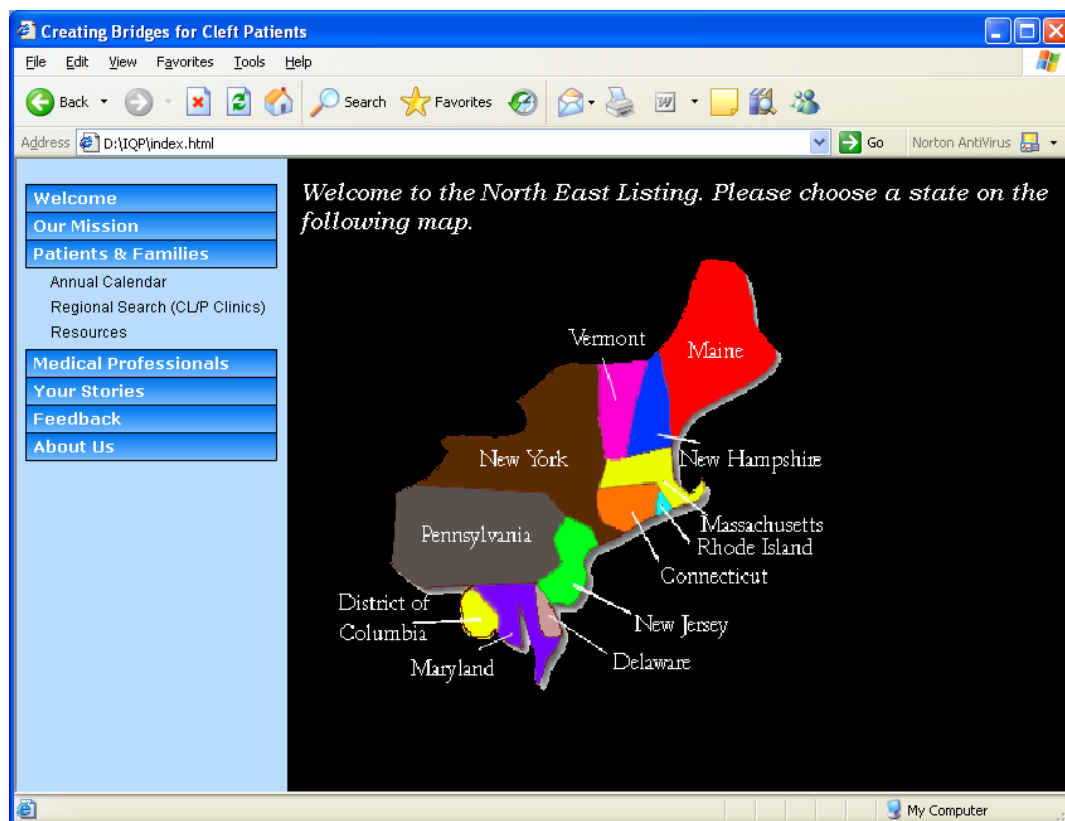


Figure 7: Surgeons Listed in the North East US

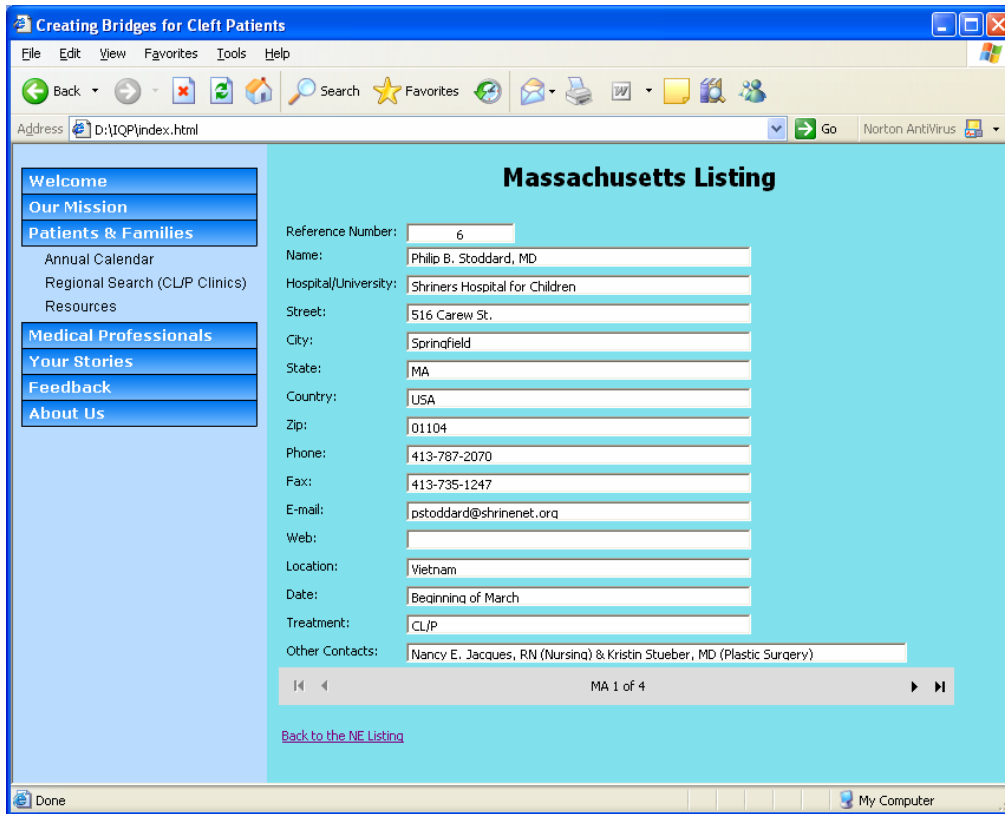


Figure 8: Listing of Surgeons in the Massachusetts Area

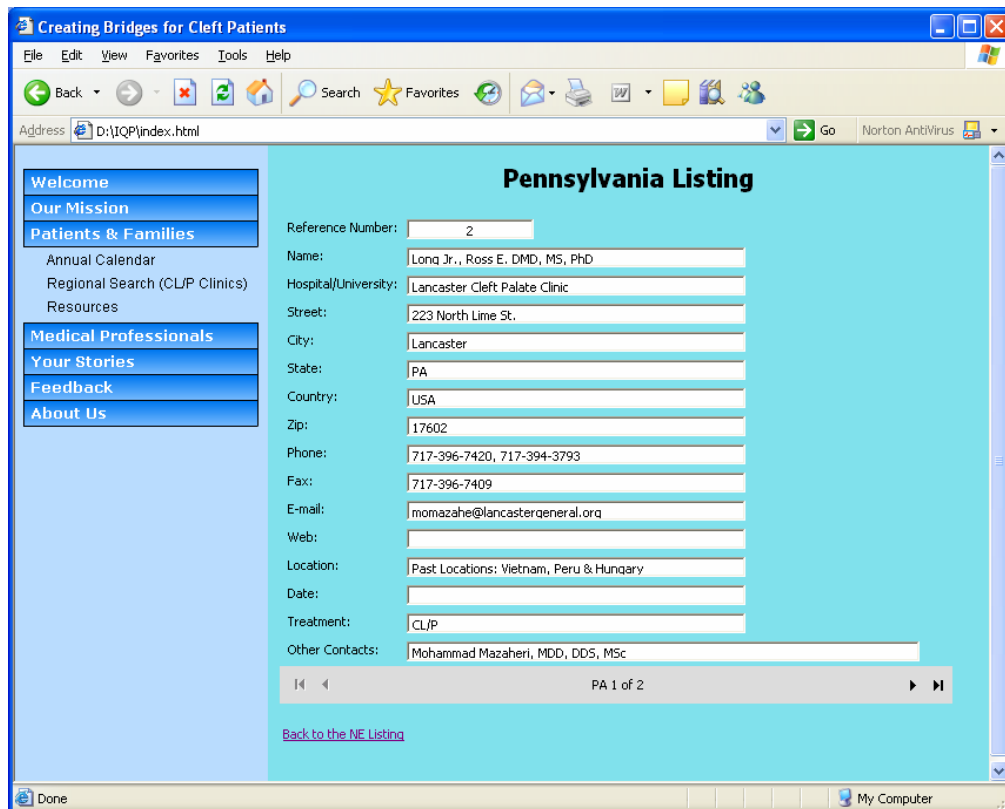


Figure 9: Listing of Surgeons in the Pennsylvania Area

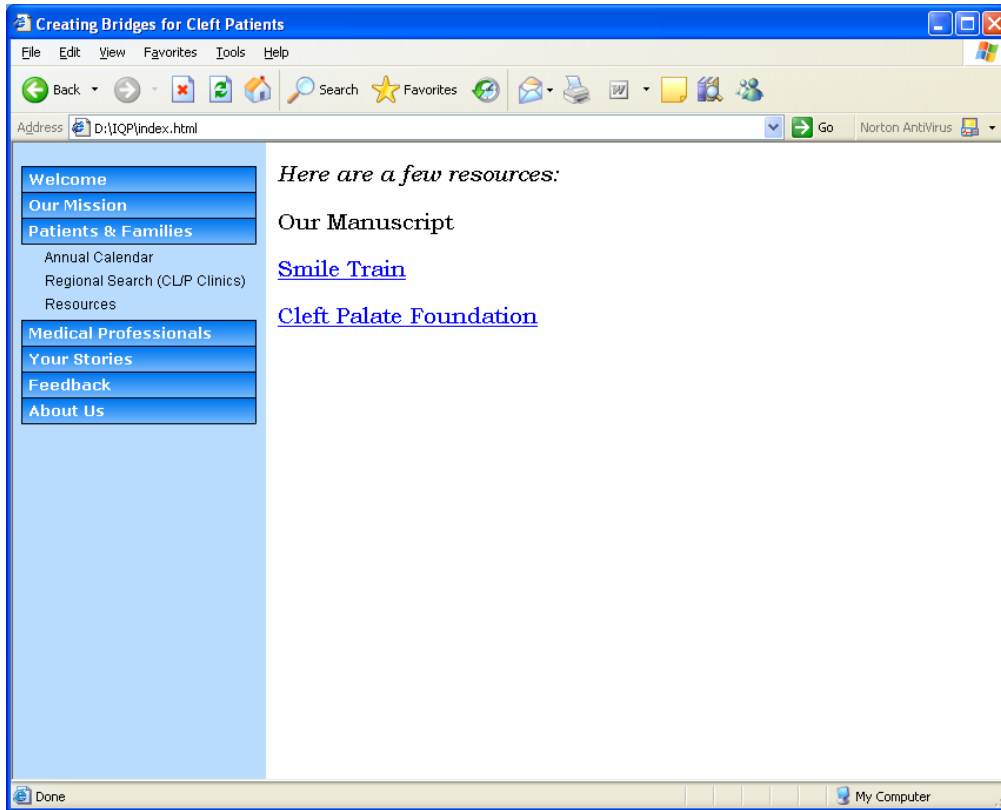


Figure 10: Other Resources

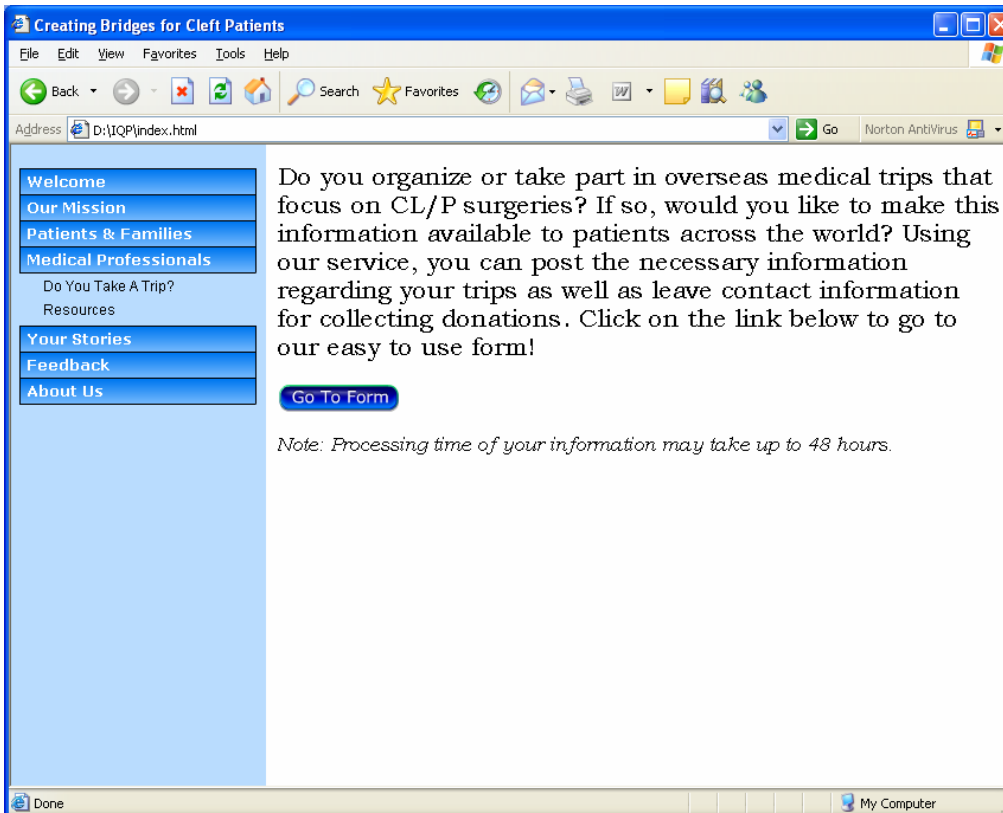


Figure 11: Medical Professionals Site

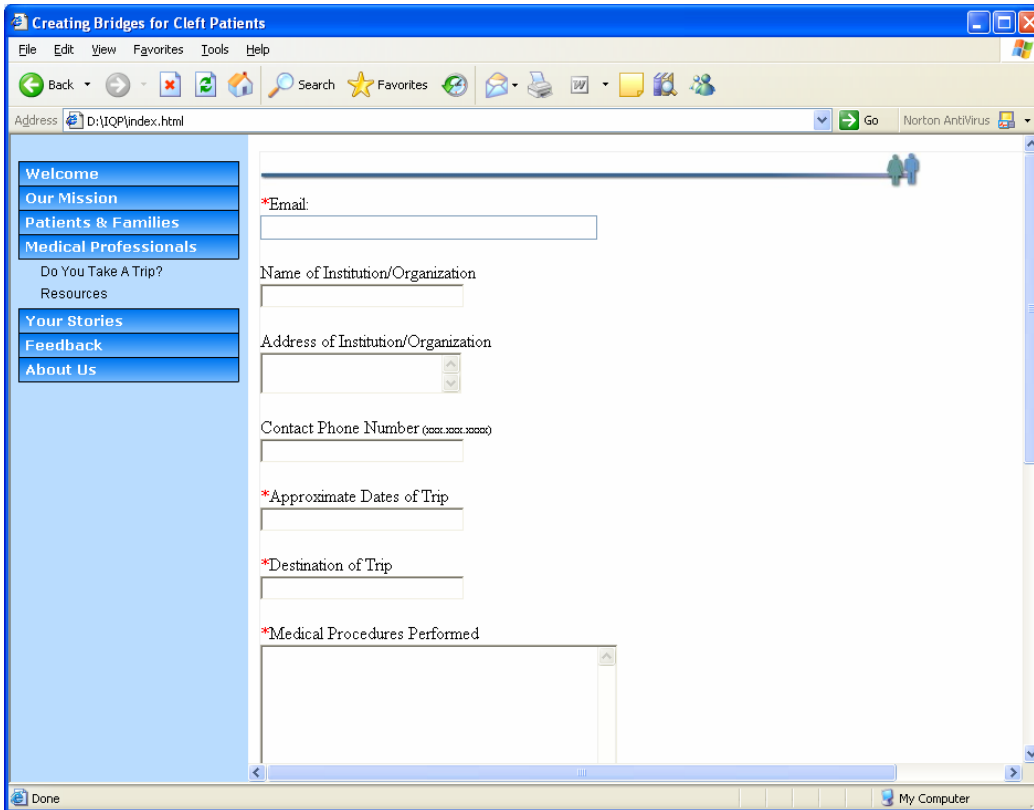


Figure 12: Submissions form for Medical Professionals

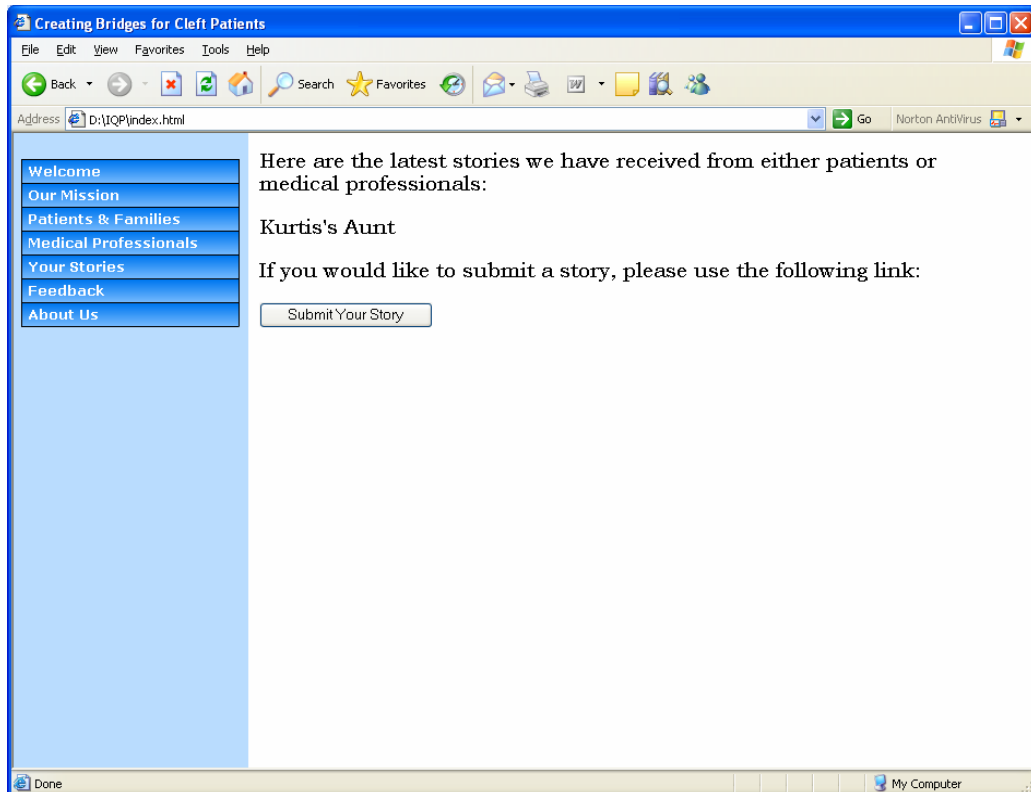


Figure 13: Submit a Story

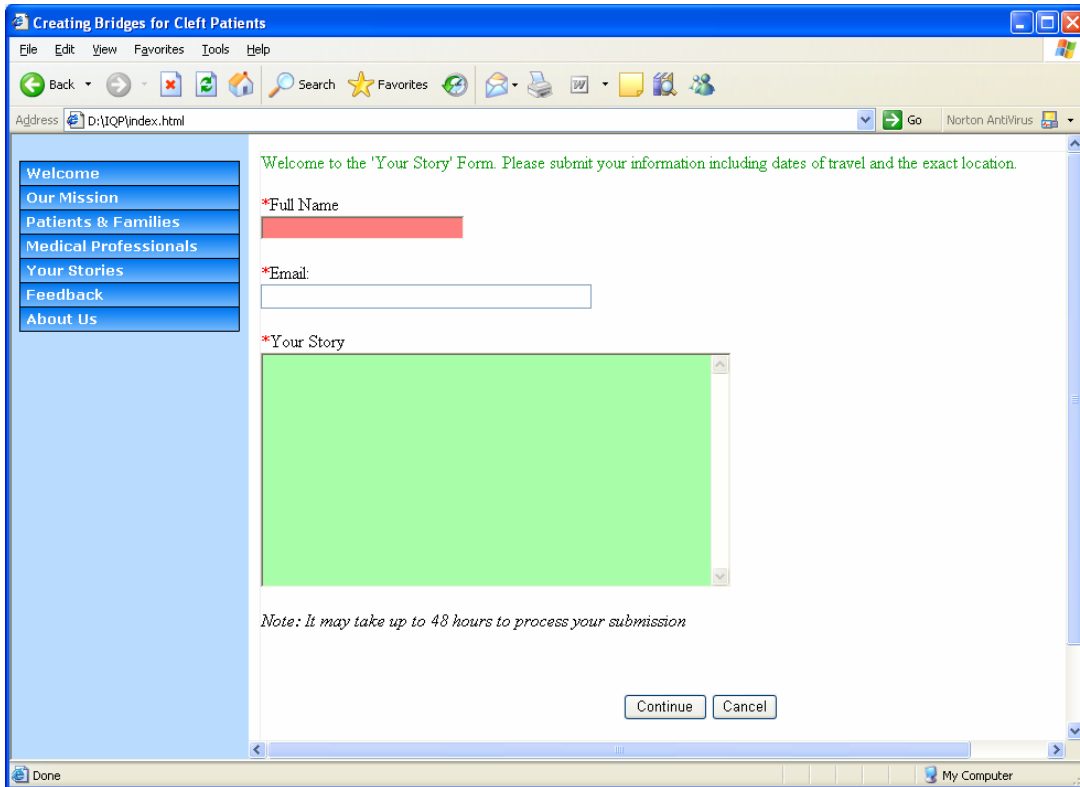


Figure 14: Story Submissions Form

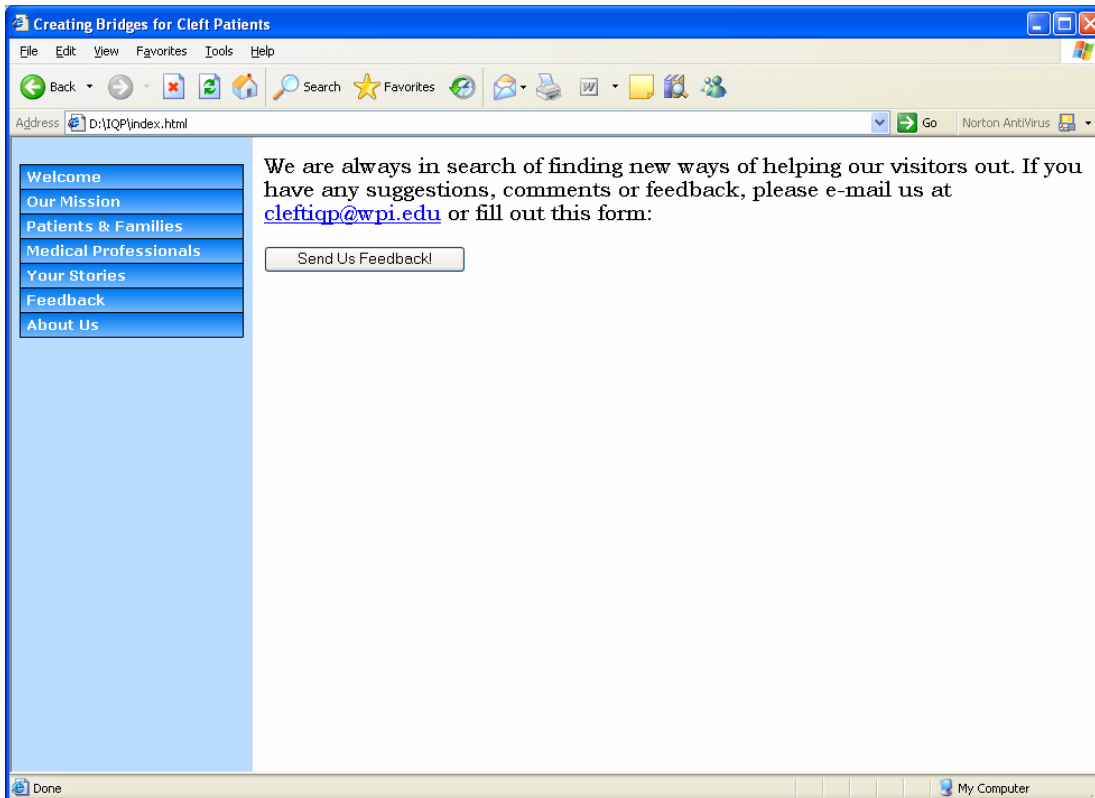


Figure 15: Feedback

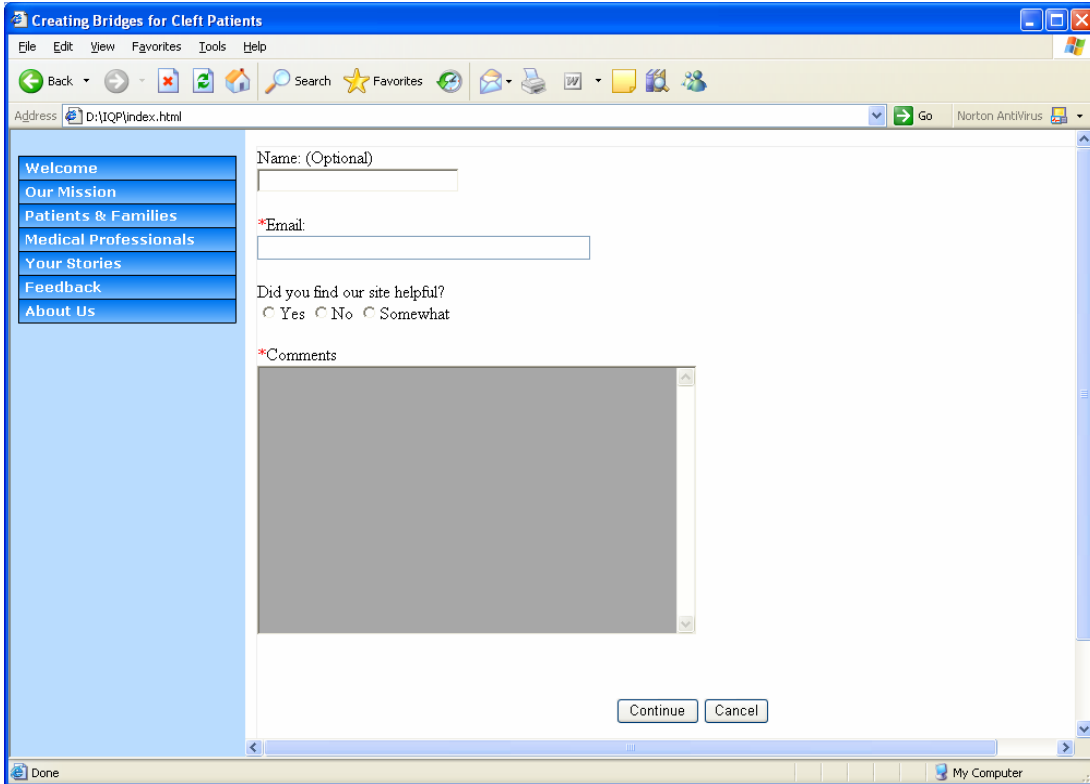


Figure 16: Feedback Form

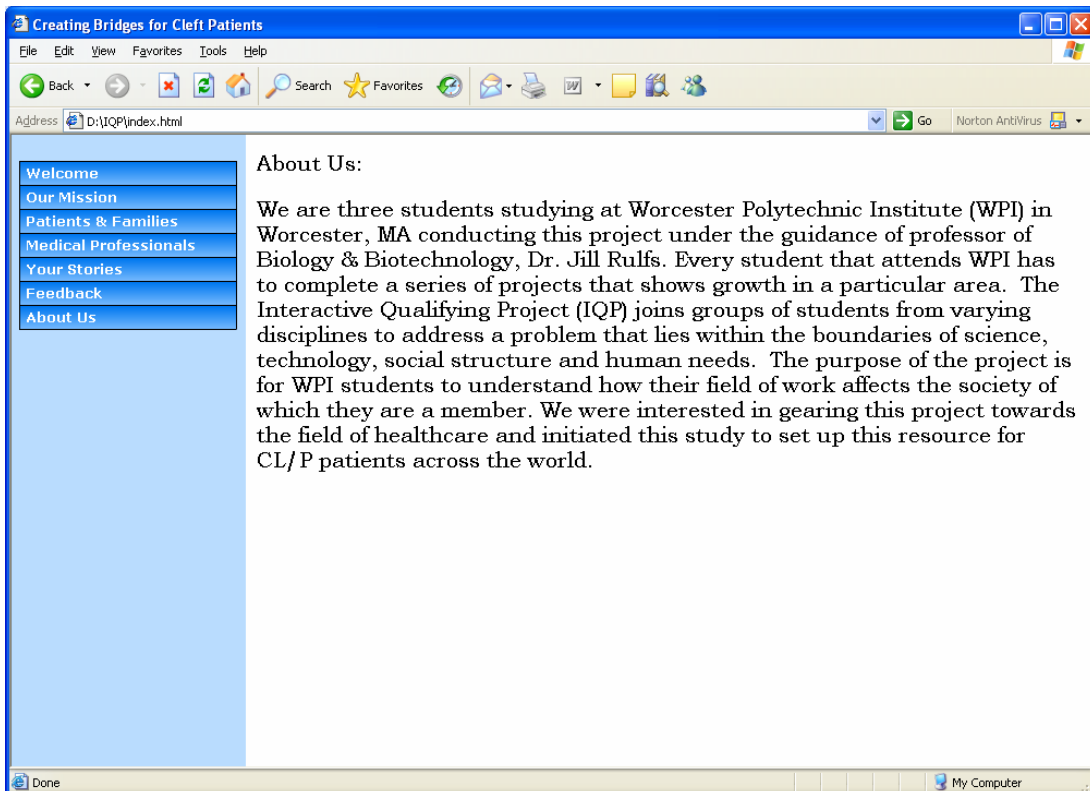


Figure 17: About Us

DISCUSSION

The initial investigation of this project began in November 2005. Over the course of the last six months, this project has allowed for a true insight to be gained about CL/P, its causes and consequences, and the problem of healthcare access and delivery in developing countries. This process has allowed for the exploration of the various aspects and obstacles of attempting to conduct a study of this magnitude. It has also brought to light some of the legal complications that exist within the health-care system relating to liability, privacy and confidentiality. In addition, the difficulties encountered in interactions with various professionals in the field have underscored the need for dialogue between the public and health care system.

The initial goal of this project was to design a comprehensive listing of the many mission trips that are involved in volunteer CL/P surgical work in other countries, particularly developing countries. Through exploration of various resources available to CL/P patients through the web, it was discovered that no comprehensive listing of overseas mission trips existed. The intention was thus to make such information available as a part of an online information center.

THE OVERSEAS TRIP

The interview with Dr. Rick Silverman allowed the team to understand how popular and awaited their trip is in the local areas of Latacunga, Ecuador. Each year, they operate on almost a hundred patients, screened from a pool ranging between 200 and 300 individuals. These patients travel with their families from the surrounding cities and villages, often walking many hours to reach the clinic. Since there is to date no database

to inform the public of such pending trips, it was important to ascertain how people found that these clinics were being offered. For Dr. Silverman's trip, the local Rotary club advertises through flyers and newspapers, which reach the literate population. Information then travels through word-of-mouth advertising. A large majority, however, are returning patients who come each year for further consultation or follow-up treatment, since most trips maintain the same location and time of year. This information indicates that there is a particular radius within which news of the trip travels, either through word-of-mouth or other forms of advertisement. CL/P afflicted children in cities too far from this 'news base' might not be informed about the availability of such help in the vicinity. Families that would otherwise be willing to travel long distances might never hear about a trip, and thus will lose a rare opportunity for their child's treatment.

EVALUATING THE NEED

This project is a pilot attempt to create a database on the World Wide Web, accessible to anyone across the world. The Internet is a tool that can connect individuals from one corner of the world to another, acting as a vast, almost infinite collection of information. By contacting doctors and surgeons involved in such missions, and obtaining the pertinent information, it seemed logical to consider setting up a calendar for patients and families who could, through one search, determine which doctors were arriving in their local area, and when.

The practicality of this project and its potential contribution to society must be evaluated. Although the internet has the capacity to allow access to large amounts of information world-wide, it is only useful to a literate population with computer access. In

countries where these medical expeditions take place, the literacy rate and availability of computer access varies and generally corresponds to the level of urbanization or development. According to the UN statistical index, countries that are considered to be least developed are given an HDI of 0.5 or below. In the nations that fall in this range, the literacy rate is determined to be at 53.3% (“Human,” 2005). However, this only indicates the ability to read and write at a level adequate for written communication. It does not signify that the population is able to successfully navigate the internet. According to statistical evidence that ranges back to 2003, the number of internet users per 100 people in developing countries was below 5% (United, 2006). Thus, if the majority of the community we attempt to reach is largely uneducated or does not access the internet (due to lack of skills or accessibility), reaching out to them through this website becomes impractical.

However, most developing countries support a government organized and funded social service network which provides services to populations in rural areas. For example, Dr. Silverman discusses the social services that are present around the city of Latacunga that provide follow-up care and support to a child with CL/P or other health related issues. Though such programs might not be as sophisticated and widespread as the programs in the United States, they are available and work in large part to facilitate the medical needs of the country. Our work could become a tool to add to the services provided on a routine, if infrequent basis, by these networks. This would enable earlier, more widespread advertisement, with the news reaching more individuals in more towns. The network of the system would also mean that the news would travel faster, allowing it to be accessible sooner than the current means of advertising so families have more time

to organize the resources to travel. A child in Salinas, Ecuador, could then have the same opportunity to be evaluated for help as a child in the destination city of Latacunga, Ecuador.

Similarly, large public hospitals and economically well-placed clinics would be able to share information that they can access through the site. Interplast, a US based organization, conducts a large scale humanitarian project in various countries. Its surgical outreach centers connect the headquarters to participating doctors in their home country. Interplast states that though “many of their surgeons are based in urban areas, most of them travel regularly to remote and underserved regions to care for patients....work in coordination with local hospitals and clinics in order to share resources and personnel” (Interplast, 2006). This leads one to believe that the collaboration between the urban areas and the remote areas is such that information we might be able to convey to a city could travel to villages and rural towns that might benefit from it.

OTHER AREAS OF PROJECT OUTREACH

A second crucial aim of the project is to develop a mechanism by which health care professionals in the United States and abroad can use this service to collaborate or arrange their own expeditions. Surgeons may have the desire to arrange overseas mission trips, but are unable to do so due to financial reasons or because of the difficulty that lies in initiating such a large endeavor. As Dr. Silverman states, “more than four months of work is required for [preparing] the seven days spent on the actual trip,” in Latacunga, Ecuador (Silverman, 2006). Most surgeons or medical residents, therefore, prefer to accompany a trip as volunteers, and pay their own way, which is usually around \$1000

per person. However, this is also difficult to arrange, unless a direct contact exists between the potential volunteer and the team leader. Dr L, who has accompanied Dr R and Dr. Silverman on their trips for several years, initially joined as a result of her friendship with the surgeons since they worked together at the University of Massachusetts Memorial Hospital. A surgeon who works in a hospital where such endeavors do not exist, or is an individual in private practice, would not have this same opportunity, though he/she may wish to volunteer his/her services. For individuals like this, who can range from student volunteers in medical universities to therapists and reconstructive surgeons in other fields, these current efforts could provide a convenient way of finding team leaders, contacting them and joining trips leaving from anywhere in the US.

Similarly, surgeons in the reconstructive field in other countries could also take advantage of the tool. Surgeons working in a developing country may use it to reach specialists with wider resources in the US, to gain advice, or to request help in a particular area. It is possible to divert a trip from its regular course if a greater need could be fulfilled in a different area. For instance, Dr. Silverman informed us that initially their team would travel to Salinas and Babahoyo, until one year when the clinic in Latacunga requested that they change their course. After that year, the team has religiously returned to the area annually. Thus, surgeons and directors of clinics like the Fundacione Tierra de Nueva in Ecuador, a non-profit clinic that “hosts almost one medical team a month”, may use the website to increase their own network of specialists who travel from the US. (Silverman, 2006) These individuals may even initiate their own program of sponsorship and contact a team that is known to travel to their country. Or, if for some inexplicable

reason, the expected medical team is forced to cancel its own plans, the hosts can attempt to request a different team, or direct the local patients to a team arriving in a nearby city or village instead. This project creates a website that could open up this type of dialogue and potentially increase the scope of CL/P medicinal care to places that are in dire need.

SPONSORSHIP

The American Cleft Palate Association-Cleft Palate Foundation (ACPA-CPF) is an international non-profit society of health care professionals involved in treatment or research of craniofacial deformities which could adopt the developed site. This would allow it to be accessible to the vast numbers of visitors that visit the ACPA-CPF site (www.acpa-cpf.org) daily, which include CL/P patients and families, and professionals in the field. We designed a project proposal (Figure 2) which was sent to the Executive Director of the ACPA-CPF Foundation, NS, by Dr. JL. Project sponsorship is necessary to both host and maintain the site, and the ACPA was our first attempt at gaining this support. Without a valid project sponsor, it was likely that no medical professional would consider sharing his/her information with us. If we could state that the ACPA was supporting or sponsoring our project, then the individuals we contacted would be more likely to take notice of these plans and contribute their information to the database.

An organization such as the ACPA, however, cannot make a decision to sponsor a project easily. The proposal must be evaluated by various departments and committees, through which comments are made and pros and cons are weighed. A decision to adopt such an initiative requires discussion and deliberation among the various branches of the organization.

Dr. JL and Dr. RD, who are primary advisors of this project, were also unable to allow their names to be associated with the template letter. As employees of a private hospital, the doctors would be breaking strict guidelines if they allowed their name to be associated with any endeavor without obtaining legal permission from UMass Memorial Healthcare. Lawyers would evaluate the risk involved in the doctors' accepting direct sponsorship of our project which would include responsibility for maintaining the privacy and trust of anyone who participates in this project by volunteering trip information. Moreover, Dr. JL's and Dr. RD's contact information would be given to almost forty-six surgeons in the north eastern coast. In turn, the hospital would also become involved in these efforts indirectly. If any user found the content on our site to be objectionable, then the reputation of the hospital would be affected negatively, as supporters of this project. Furthermore, it would be the hospital's responsibility to ensure that all the information that is collected and posted on the on the website is true and correct to the best of their knowledge. If any of the information is found to be erroneous and results in complaints from the visitors, then the hospital would be responsible and potentially be at risk for legal action.

Obtaining legal approval to sponsor the project could be possible, but this process is lengthy and complicated. We then requested Dr Rick Silverman, Dr. JL's friend and colleague who is now in private practice, for his help. Since Dr. Silverman works in private practice, the liability and privacy issues were considerably reduced. No other parties are involved, and so it was Dr. Silverman's own decision to involve himself with the project. His approval allowed this first obstacle to be overcome.

VOLUNTEERS IN PLASTIC SURGERY

Coincidentally, before we dispatched the emails, Dr L received an email from the PSEF Volunteers in Plastic Surgery, a part of the American Society of Plastic Surgeons (ASPS), which she forwarded to us. The email was from Dr. AVB of the Volunteers in Plastic Surgery Committee, requesting surgeons for their input relating to domestic and international volunteer service. According to the email, the committee “wished to collect contact information on the organizations/individuals that sponsor volunteer opportunities to build a specialty-wide calendar of potential service trips...to serve as a resource to member surgeons who would like to participate in a trip.” A link to an online survey was included, and surgeons were requested to simply fill out the form and submit it. Their initiative was very similar to this project. In fact, the questions on the survey were aimed on collecting the same information we wished to acquire. The primary difference was that, according to Dr. VB, their efforts were geared so that the final product would be a resource to fellow surgeons who were members of the ASPS, while ours was aimed at helping both the medical community and CL/P patients and families. While we wanted our site to be open to the general public, the PSEF site would be restricted to ASPS members. In addition, while this site had to be limited to only CL/P trips, the ASPS-PSEF could include all fields of plastic and reconstructive surgery.

We could not continue without exploring the ASPS-PSEF efforts. It was important to immediately notify Dr. VB about our project and its similarity to their plans in theme and structure. We realized that the potential of this project to reach the community and fulfill its role would significantly increase if collaboration with the ASPS-PSEF was arranged. The ASPS, like the ACPA, is an organization of undeniable

reach and influence. Since there had not yet been a response from our request to the ACPA, we realized that this would be an opportunity to once again attempt to gain sponsorship for this site. The PSEF seemed ideal, since their goal was to broaden access to the information on international trips to help the field of plastic surgery.

We also considered the fact that even if the PSEF did not wish to collaborate, it was important for us to inform them of our efforts. We wished to avoid having our emails follow Dr. VB's emails so that doctors who had already been contacted by a reputable organization, known to them personally, would not receive an apparently redundant request from an unknown entity. If doctors supported the ASPS-PSEF efforts by filling out the online survey, it seemed less likely that they would submit their information to this project. Searches of the ASPS site also revealed that all forty-six surgeons on our contact list were ASPS members. Thus, all had probably been contacted by Dr. VB, and this factor might have affected the response rate significantly. One of the doctors informed us that he would not repeat the information for us, but we could retrieve it from the ASPS.

Dr. VB was contacted with a description of our project, suggesting a possible collaboration and offering our free services to their organization. He informed us that their committee was still in the data collection stage and asked us to continue to update him regarding the progress of this project. A potential collaboration could be discussed in the future.

RESPONSE RATE

As indicated in the results, after using both email and telephone calls to surgeons, the response rate was only 47%. It is important to consider the various reasons for receiving absolutely no response from almost half of the contact list. We had requested that even if the doctors were not interested in participating in our project, he/she acknowledge receiving the email and if possible inform us why they could not do so. There was a very low rate of such responses, as stated in the results section; we received only three email responses. Two of these stated that they did not participate in such endeavors. We did not receive any acknowledgement from the remaining forty-six.

Primary Attempt - E-Mail

The primary explanation for this non-responsiveness may be the lack of priority placed on an e-mail received from three unknown students. Surgeons with busy work schedules can not be expected to spend much time on an email received regarding a 'possible' project. Even if they are interested in the concept, replying to a fairly lengthy email with a detailed response means time taken out of their day. In most cases, the email reaches a secretary who filters what is or is not important. This would give high priority to emails that are directly related to current cases or similarly important situations. Over a period of time, any email not of immediate importance will get pushed back, meaning that the individuals we were actually trying to reach might have never seen the email. When we placed calls, none of the twenty-three individuals we spoke to mentioned the email or acknowledged having heard about the project before, though each time we began with the statement that "this was a follow-up to an email sent two weeks before." This

cannot be because of a faulty email addresses—no emails bounced back and we confirmed the email address from each doctor before ending the call. Thus, we are led to conclude that emailing was an ineffective way of introducing this project and requesting for information in almost all cases.

In retrospect, the format of the template email may also be at fault. Prior to the ASPS-PSEF email, we had not considered the idea of a survey that can be sent as a link. This means that surgeons can submit their information with a few clicks and minimal typing. Our email was designed carefully and edited several times to be as short and concise as possible. We felt that none of these sections could be eliminated, lest it result in confusion or sound vague to the reader. To ensure lucidity of our point and the goals of this project, the email was somewhat lengthy and might have contributed to the poor response rate.

Secondary Attempt - Phone Calls

Although only one of our contacts explicitly directed us to acquire trip information from the ASPS, thereby confirming he had already participated in their survey, it can be safely assumed that our efforts were probably an unwelcome repetition. This would explain the extremely small response rate to the email. Phone calls, where we directly spoke to the doctors and explained who *we* were in greater detail, worked better. Phone conversations allow better understanding and dialogue so that any apprehensions or hesitations can be conveyed and answered directly without going back-and-forth as one does through email. Through the phone conversation, we could immediately determine who would be interested versus who did not wish to be contacted again. More

importantly, because of the close network of craniofacial surgeons in the area, we were often directed by one surgeon to another, who was often not in our database, for better information. Emails did not generate such a response. Surgeons who did not participate would be more likely to delete the email without giving it a second thought. Over the phone, however, if one clinic did not participate in such trips but had knowledge of a different team that was known to participate, then the former would share contact information of the latter, thus proving to be an additional resource.

PRIVACY & LIABILITY

Apart from these technical points, there are several other factors that could prevent a surgeon from responding with his/her trip information. Privacy issues are of great significance. All of the information we obtained of these surgeons was from websites where it was publicly available. Any one could have access to the information and use it as desired, no special permission was required at any of these sites (www.acpa-cpf.org, www.cleftline.org, www.smiletrain.org, www.faces-cranio.org). The families of CL/P afflicted children in the U.S. can and must use this service to reach a doctor in their area, doctors may have been wary about providing this information to an unknown entity. Even though our advisors could be directly contacted in case there were any need for authentication of our project, doctors may not have had the time or desire to attempt to verify the specifics of our project.

In this situation, where the individual is not exactly sure where the information is going to appear, it is natural to be wary. When we called, there was no real assurance that we actually were who we claimed to be—even if the doctors contacted Dr. Rulfs or Dr.

Silverman, there is no way of confirming that the individual on the phone is actually one of the group members. Despite this, the offices we spoke to were generally forthcoming in sharing information over the phone. However, a large majority of the phone calls remained unreturned. Messages were left on the answering machines of twenty-seven offices and clinics and we only heard back from two of these offices, despite waiting more than two business days.. This indicates that they did not consider the message to be of much significance or did not feel comfortable in speaking to us about our project.

The fact that we did not have a sponsor to host our website at the time also worked against us. It diminished the trust factor since most professionals would be cautious about associating their name to a project that did not have any tangible support from an established source. In addition, the future of this project is uncertain as it may never be hosted. Since we cannot assure the doctors that their information will actually be useful, it dissuades them from giving us their time.

FUTURE OUTLOOK

Over the course of this project, several obstacles were encountered that raised important questions regarding the complications involved in designing a system for the health care field. There are several subjects that can and should be explored further to allow a project like this to be more successful in its aims.

CONTACTING A HEALTH CARE PROFESSIONAL

From the results of this project, it was inferred that contacting a surgeon by telephone provided a dramatically higher response rate than attempting contact via email. However, almost half of the surgeons contacted did not respond at all. This leads one to question what the best method of contacting a health care professional would be. A future study may look into the various methods of contacting such doctors to determine the preferred and most successful means to communicate and collect data. Perhaps a survey can be set up and administered to a representative fraction of this population, which in this case would be the population of craniofacial surgeons in the north east. Evaluation of the results from this survey may identify strategies that could increase a response rate in projects like this.

LEGAL ISSUES IN THE HEALTHCARE SYSTEM

Liability and privacy issues proved to be a significant hurdle to advance the project. Gaining a better understanding (perhaps directly from the legal offices) of the various factors that restrict information sharing or of the procedures that must be followed in information collection, is vital. This understanding would allow development

of an unambiguous agreement between the providers and users of this information, be it a hospital and the webmaster posting the information, or a visitor to the site desiring to post the details available on another site. If the rules are identified and understood, then assurances can be put in place, especially where issues as sensitive as maintaining privacy and trust are concerned.

EXPANSION OF THE DATABASE

The current listings are limited to the twelve north eastern states. If the project were to continue, future work can be conducted by expanding the project to more states. This data collection may be carried out in many different ways. One possibility is to concentrate on the geographically larger states (Texas, California, etc). Another method might be to start from a different coast and move towards the central United States, or vice versa. It seems reasonable to give priority to any large or wide reaching endeavors leaving from established hospitals or organizations, such as Interplast, which has its headquarters in California. Thus, any search to add craniofacial surgeons to the database should focus on including these teams first. It is likely that trips sponsored by an organization like Smile Train or Interplast have funds, resources and experience that make them crucial to their destination. Inclusion of these trips in our database thus adds to these efforts. Our own search was initiated through exploring the work of these and similar organizations.

SPONSORSHIP

The issue of sponsorship is one that is integral to this project. Without being hosted by another site, the web pages designed do not fulfill their purpose, as they remain inaccessible to the public. As discussed in this report, attempts have been made to collaborate with various prominent organizations in the US, aiming to find one willing to include our website as a part of the CL/P resources they offer. At this point, we have been unable to confirm such sponsorship. Hospitals that specialize in craniofacial care or clinics with wide resources would be ideal candidates along with other prominent plastic and reconstructive surgery-based organizations. A more attractive and brief proposal should be designed and presented, perhaps including the option of arranging a meeting and personally describing the project should be considered. The project can also be analyzed for its philanthropic potential, since that factor might influence the decisions an organization makes. Thus, the overall projection of this project might be improved after analyzing the factors that could positively influence a decision for sponsorship.

Once an organization is able to host our website, then this product has the ability to be expanded to perhaps include more features that may allow visitors to search for CL/P resources in a more user-customizable fashion. This may include a forum where visitors can discuss craniofacial-related issues with one another or even a different system where doctors have the ability to discuss and share their work and experiences with each other, especially those pertaining to their overseas trips. This would allow a unique exchange of ideas and knowledge that would educate those traveling on what to expect and perhaps encourage more professionals to become involved with such endeavors. However, improving on this model in such ways requires skilled webmasters who will

also be able to constantly update and adapt the site to the needs of the visitors. Both of these can best be provided by a professional organization.

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APPENDIX 1: INTERVIEW WITH DR RICK SILVERMAN, MD

March 21, 2006

Q: How long have you worked on these trips?

Rick: I've been involved with these trips for 15 years. The first time I had the opportunity to join one was in 1991, with Dr Rothkopf. I was a resident at the time. 2 nurses and 2 anesthesiologists accompanied us, 6 people in total and we did 30 surgeries in the week. That was when I learnt the process of organizing these trips and now my trips are much bigger, almost 26-28 people. We go for 8 days but it takes 4 months of preparation and clean up for that time. We always leave in the first week of February (February 4).

Q: Who organizes it on that end?

Rick: It is organized by our hosts down there who are Rotary members in Latacunga. They advertise the event by putting up signs, ads in the newspapers, etc.

Q: How do they select the patients and what is the criteria used?

Rick: The Rotary members are responsible for the prescreening process for the patients at their end to get 200-250 people into our first clinic. In Latacunga it's a very loose process, they just put up signs to attract anyone with problems of a plastic surgery nature, including congenital problems like CL/P. So we'll get patients with broken noses or hands or ears, and we can't treat all of them. We have to be strict and turn away anyone who does not have a congenital problem, or have problems that will take too much time. This time we only accepted 98/250 cases, which is hard but has to be done. This year in September we will be going to a different city in the jungle, Puoyolo, and they will have a much stricter screening because they need to provide transportation through boat to those selected. So a medical professional will actually be screening them for problems.

Q: In your experience, is the incidence higher in Ecuador and certain places?

Rick: I will tell you more about that, but yes, that is very true. It's a genetic issue, dealing with populations and also often with intermarriage. CL/P incidence is highest in the Far East and Asia. It's believed they came here to populate the Americas, and Native Americans have a certain incidence and rate which in South America stays high, but goes down when mixed with the European race.

Q: How do you prepare for these trips?

Rick: On our end, anesthesiologists start salvaging drugs, contact drug companies, contact suppliers months in advance. We collect supplies in the UMass Memorial Hospital and in the St Ives Hospital in Boston. The packing process starts sometime after the holidays. For example, two nurses have already started collecting and salvaging instruments, etc.

Q: Who does the team consist of?

Rick: Of course, the anesthesiologists are very important and are the limiting factor for our surgeries so we need 2 or 3. The surgeons include Dr L and me, a hand surgeon, and we also have 3 nurses, a former trainee, 1-2 plastic residents and a general surgery resident, and volunteers. Dr R's teams are still quite small.

Q: How are their expenses covered?

Rick: They each have to pay their own airfare and living expenses, which comes out to be about \$1000/person. Living expenses are usually free but we chose to start living in a resort starting this trip, so it's \$48 a night. We raise money from friends and family for the supplies, or our own trip. I pay for the 3 nurses that go.

Q: Are there medical professionals like yourself there who help?

Rick: We're hosted by the Rotary Club in Latacunga. There is an internist among them who is involved with the prescreening and the post op follow-up. Earlier there used to be a woman who was a plastic surgeon, but now she has moved to Quito (another city) full time. She set up a hospital there, where we go sometimes, its called the Fundacione Tierra de Nueva. It's a hospital in the southern part of Quito for people who need health care that they can't afford. They host groups like ours almost once a month. They have an operating room, and storage areas for these groups.

Q. How do you choose the location?

Rick: Originally we went with Dr R to Guayas, then to Babahoyo, then I led a trip to Salinas. The next year we were supposed to go to Babahoyo but ended up going to Latacunga. And it was a very beautiful place, and the Rotary group was great. We went back in two years and continued going back.

Q. What about the language barrier?

Rick: I speak very good Spanish, and Robert Gross, an anesthesiologist, is also fluent. There's a couple people now who have become pretty good with the language. We can take translators, and we had a medical interpreter with us this year. Its not a big problem because now we have enough people who speak the language.

Q. Do the patients have to pay anything for the services?

Rick: Not in Salgado, where we also go sometimes. In Tierra de Nueva I know they pay small donations based on the financial status, that's how the place affords itself. In Latacunga you don't have to pay except for living expenses. Even if they do pay some amount, they get a great service for a small amount. Some families actually happen to be

more well off than others but still need a special kind of help. Some families actually need money and we end up actually giving some money.

We take our supplies with us and so the hospital or patients don't have to provide it. We used to take own fluids but they have expiry dates and they are also very heavy. Now we just buy it there along with the narcotics. Drugs are much less expensive down there, anyway, so it makes sense to do that.

Q. So how much is this surgery worth there?

Rick: Surgeries are much cheaper there in comparison. It would be around \$300 while in the US it would range from \$3300-\$3500. But for them, that is still quite high!! They have to buy fluids, medication and suture material even if the surgeon was doing it free. So when we go we have the privilege of performing surgery on them in exchange for giving them these supplies.

Q. What do you tell patients before they go into surgery?

Rick: We don't give them as detailed an explanation as we do here. It's hard to do so. They often have a vague idea of what is going to happen. We tell them "this is what we're going to do, and you can expect this." They are not like American patients, they have a very different perspective in that culture. Class issues are hard to understand for us. Physicians are very respected there, placed on a pedestal. Even if the child dies, which has happened a few times, the parents are still grateful. Once a mother actually brought us gifts even though her baby died. She was grateful that the lip was fixed. They also won't tell you if the kid has any other health problems because if you say yes then you won't be able to give them an operation. And this operation means everything to them that is also a cultural thing.

Q. Are there any dangers to your team and you?

Rick: There are strictly speaking two travel advisories. There's a war between Peru and Ecuador for almost 15 years now and then there are pick pockets. Its not a big issue at all though. We have not had any problems, except 2 people have been mugged but you can get mugged anywhere.

Q: Once the team has left, who follows up with the patients who need it?

Rick: Well, our initial clinic is on Sunday, and then we operate Monday to Friday. The final clinic is on Saturday. I print out a list before I leave, and leave instructions for patients who need them. I try to leave the place so sutures are easy to remove or do not need to be removed. There are people there who can help. The surgeon from Quito will come down sometimes for important things. We try to work it out so the child does not have to stay in the hospital for longer than that week maybe. A speech therapist accompanies us often for the week to help with the issues. We can arrange for physical therapy there sometimes. Orthodontist work requires that the family have resources. There is a social service system there, which took us 15 years to realize that there is help there once we leave, a lot of resources for them. If the surgery takes several stages we do it year by year, stage by stage. For example ear surgeries require a frame, then skin work, then other things, and we do it in 3 stages. Patients come back themselves, on February every year.

Q. Any difficult decisions you've had to take, stories you have?

Rick: Like I mentioned before, we often have to turn people away, like rhinoplasty patients because its so time intensive and we are mainly there for congenital problems. We have to think it through—what is most efficient for these patients. Like boy ear

surgeries over girls—girls can grow their hair long to cover a misshapen ear and so I have to restrict myself to only the boys. Sometimes, just to be treated is a big issue for the families, and they'll keep asking.

I remember the first time we went, it was a very interesting experience. We weren't given any instructions and put into a room and we ended up using beer instead of water to brush our teeth! Now of course we are very familiar with the entire setup, the place, the trip. Its like any other trip you take.

There was this two year old once who had his knees badly bent and the deformities in his feet caused a lot of problems. We operated on him and he took his first steps that week.

The whole room was in tears as he tried to get to his mother in tears. It was a great moment. A lot of these families will request us to be godparents to their children, and we agree, but its strange because I'm Jewish!

APPENDIX 2: INTERVIEW WITH DR JL, MD

March 28, 2006

Q. Could you give us more information on the reason behind the incidence being higher in some areas versus others?

J: We don't know too much about that. We know what nationalities seem to have higher incidence—the Asians and the Hispanics—which is also supported by migration studies, but we don't know where the genetic mutation was generated. It had to mutate somewhere, because the African population is almost absent of any cases, and that is the oldest population. We also know that it probably wasn't one single mutation, but a series of linked mutations that led to the disease, otherwise it would have been identified by now. They're looking at multiple families, trying to find different potential genetic links, its quite complicated.

Q. Does maternal diet play a role at all?

J: No, its not thought to be. Although, magnesium levels have been tested in water levels, and might have a connection. Alcohol and smoking (if they are a part of your lifestyle) have been known to contribute. So has the antiseizure medicine Dilantin—it can result in a 10% increase. Any of these can lead to CL/P if it affects the fetus in the first trimester of the pregnancy. It's assumed however that all cases are genetic and/or familial, because there are a lot of variables to deal with. The vast majority of afflicted children, almost 80% plus, are born to a family where there is no other cleftie.

Q. What is the general recovery time?

J: For the cleft lip, the babies are 8-10 weeks old, and they usually often go home the same day. The recovery is very quick, and they are on pain medication only for a few

days. Cleft palate takes more time and is more painful. You can imagine yourself burning of the top of your palate down to your bone, and that would be the pain equivalent.

Luckily it heals quickly and once it heals it stops hurting.

Q. What about children who need multiple surgeries?

J: There are usual standard times that we'll intervene. The lip is repaired at 10 weeks, the palate at 10 months, the bone grafting is done at 9 years, any touchups are done in between, and the ear tubes are placed when they need them. We can give the families an overview. Usually if there's both a cleft lip and palate then we tell the parents that they're probably looking at 12 surgeries over the course of the child's lifetime.

Q. Is there always a need for speech therapy?

J: Not ideally, but the majority of time. Usually when the CP is done at 10 months, the child has not been speaking yet, so you usually often wait a year and see how they're babbling. And when they start using words, you hear how it sounds and if you feel it needs help then you get speech therapy to help with the modality.

Q. Are there any problems that would haunt the child, apart from the social issues, if the surgery was not done?

J: Just speech, speech and social stigma.

Q. Are there diet problems in CP?

J: No, if they do have problems with eating, it's a red flag that some thing else is going on, a neuro deficit or a learning problem, or a swallowing problem. If they're not able to learn to eat then its something else.

Q. In terms of insurance, if the CL/P is not so severe as to be classified as a functional necessity, will the surgery not be covered?

J: Well, we have problems with that sometimes. Maybe not so much with the primary lip repair, because if there's a hole in the face the insurance companies will cover it, even though technically the child can eat and speak fine. But the insurance companies usually end up paying for that, it's the touch ups that they may or may not cover. Sometimes the scar might be too apparent, and the child is ready to go to school, but more touchups might be needed for the look. What parents have a lot of trouble in is the orthodontist work, and for an amount of extended speech therapy. Depending on the child's age, the child might be receiving speech therapy at school but not all therapists realize the modalities of a child with cleft, and the insurance will not pay for another speech therapist. The child might sometimes be understood, but sound very nasal (its distinctive) and the quality of their voice is affected. So the school speech therapist might not be able to help anymore, and so getting them the 'advanced' speech therapy directed to that problem of hypernasality or hyperresonance is either not offered in school or not deemed necessary, since its not a functional impairment.

Q. What would be the approximate cost for the surgeries?

J: For all 12?! You mean if the insurance doesn't pay for it? I've never calculated it, but I'm sure it would come to a quarter of a million dollars. Most patients won't do it if the insurance companies won't cover it. They might be able to afford the orthodontist work, but surgery on the lip and the nose that you can't get covered they probably won't do it.

Q. Is it covered fully if under insurance?

J: Depends on the insurance company.

Q. How much of a role do you play in that? Are you going back and forth to prove the need?

J: Yup, and with the speech, they need an MD to validate that services are still needed. We have to document all the information about what they need, and the fact that their school speech therapist is not adequate and why.

Q. What about patients with Medicaid? Are their services covered?

J: Yes, they do. A lot of the issues with Medicaid is that they reimburse differently, what they pay for the services might be different than what other insurance companies pay. That's fine for some services but we have a problem nationally right now with dental and orthodontist services. They are not taking Medicaid because from their perspective its so low that it doesn't even cover the paperwork it takes. They feel that they lose money instead. The dental school or public hospital, you might have to take it, but if you're a private practitioner you can make the decision not to take it. Most orthodontists and dentists don't take it, and so patients with Medicaid have a hard time finding one. There are some who will set aside some free surgeries, do it pro bono, because its more costly to do through Medicare than free. They tell me, and I know that this much of their budget is going to be pro bono, how many patients they'll accept every year.

Q. Are there any dangers after surgery to the patient?

J: Nothing is risk free. The lip repair is fairly straightforward, its all in the front. You could have problems with bleeding or infection, or the scar. But usually the babies just go home the same day. Palate repair always stays overnight, since we're doing surgery inside the mouth and we're worried about bleeding or swelling obstructing the airway. After monitoring sleep apnea and oxygen that night, if they are stable, then we'll send them home and just make sure they are taking enough liquids. They are hurting and

taking a lot of pain medications but they have to make sure to take a lot of liquids and not get dehydrated.

Q. Are there any long term issues?

J: Well, not long term. You can have late problems with palate repair when the child grows and the bone grows or if its stretched in orthodontics. You can have a hole created later in one of the touch up repairs. You can have issues, but not health problems.

Q. Is the scar usually not evident?

J: Well we're trying not to make it too evident. Ironically, patients with the highest incidence of clefting (Asians and Hispanics), also have a higher incidence of having problems with their scars-thick scars, contracted or fragmented scars, etc, especially the Asian population. So we do a lot of things with these high risk population, we tend to be very aggressive with the parents about scar cream and massage, and remedies like that.

Q. Is there any certification of any kind needed for a CL/P specialization? Should parents look for something before choosing a surgeon?

J: The quick answer would be no. Except, having had some experience in CL/P repair. There are surgeons that come from plastic surgery only residency or ENT only residency, some who come from oral surgery programs. You should have had at least that background. There are either pediatric plastic surgery fellowships or craniofacial fellowships that give added experience, and parents can ask about that. Ironically, some of the big people in the field, the old established surgeons haven't had any of that, because the fellowships didn't exist then but they were the leaders in their field. Its difficult to figure out the track record of the surgeon, but it helps to look at other patients that have been treated. I used to be able to use a "before and after" book but now there's a

photo consent form that needs to be used and there are a lot of specifics attached to that that's hard to obtain. So now I don't use photos, and that's hard for families to understand. I can refer them to a child I treated and they can contact them and talk to them about it. Then it's up to the family to decide if they want to show their child. Most families are going on the internet now to find out.