Funding a Smile

Increasing awareness of cleft palate/lip by explaining its causes, impacts, pre and post-surgical care, case studies, and raising funds to contribute towards Operation Smile’s cause.

Tag Words: Cleft, Damage, Soft Palate, Lip, Operation, Smile, Plastic, Surgery, Benefits

Authors: Sunke Sagar, Megha Master, Romal Vaidya, Nidhi Radia with Julie M. Fagan, Ph.D.

Summary:

Cleft disorder is the most common birth-defect which is found in “1 of every 700 infants.” Cleft palate is a gap on the roof of one’s mouth. Cleft lip is a split on the lip between one’s mouth and nose. There are many organizations in the United States that support and help these individuals financially. This disorder can impact an individual socially, professionally and academically. These organizations help patients to overcome such problems. Surgery is the best solution to fix the cleft palate and cleft lip as surgery can restore one’s smile. There are two options one could opt to take. The first option being going through surgery, the other option is non-surgical which is just getting speech therapy. However, the physical disfigurement remains. The cost of surgery can cost anywhere from $5000 to $20000 depending on an individual basis and severity. With Operation Smile, it costs about $240 in donations to get a surgery done for each individual. The results after surgery are quite recovering, as there may be a scar and stitches which are put in around the palate and lip area but eventually the stitches will be taken out or be dissolved within five to seven days. Eating should be limited as the scar needs to be taken care of, and fluids need to be taken in more regularly then solid foods. Each case will be different as a whole, as recovery time and post-surgical care is on a severity basis. Our issue focuses on raising awareness as more than fifty percent of people interviewed at Rutgers University at New Brunswick, do not know about cleft palate or lip. In addition to spreading the word, we decided to raise money or funds by participating in an event organized by operation Smile at Rutgers as part of our community service project. We took part in it’s annual stand-up comedy event. The comedy show is a way to entertain people and raise money for a good cause. About 10-15 volunteer comedians perform for about five minutes each and tickets are sold at $5 dollars to people who are affiliated with Rutgers and $7 if they are not affiliated. The show runs for about an hour and half to 2 hours. All funds raised at this event are sent to the Operation Smile Foundation which would then be used for helping people with cleft lip/palate.

Video link

Smile Presentation: http://www.youtube.com/watch?v=O-pUKMOtx2Q
The Issue: Cleft Palate

Soft Palate damage and statistics of affected (NR)
The soft palate is the soft tissue building the back and top part of the mouth. The soft palate can be differentiated from the hard palate, which is the anterior part of the mouth which contains bone while soft palate doesn’t. It is also recognized as velum or muscular palate. Muscle and connective tissue build up soft palate. Since both muscle and connective are part of soft palate, it gives flexibility, mobility and support to the mouth.

There are 4 main functions of the soft palate and they are:-

1) Articulation: is speaking clearly by pronouncing different syllables. This is the common disorder found in a person with soft cleft palate damage. It is a problem mainly with phonetics and varies from one individual to another.

2) Speech: - Speaking is a daily life process to communicate. It needs support of soft palate to create sound for the speech. This happens because there is no division between the nasal cavity along with the mouth.

3) Swallowing: - is a process when a person intake food and pass through mouth and then inner part of the body. Since infants lacks division between the nasal cavity along with the mouth infants have weak sucking ability. Hence, feeding requires modification such as intake a lot of air while feeding.

4) Velarization: - it deals with pronunciations mainly consonants. To pronounce certain syllable tongue needs to move up to palate.

In general, cleft describes 'split' or 'separation' (3) or 'cut' between two organs. During beginning pregnancy independent sections of the face grow separately and that time connects together. The lip normally completes by 5 to 6 weeks later embryo, along with the palate by 10 weeks. If several portions do not connect critically, the effect is a cleft. Cleft lip and cleft palate involve the fourth superior everyday birth defect in the United States. “1 of every 700 infants” (7) is affected by a cleft lip and/or cleft palate.
There are three main types of cleft:

1) Cleft lip without a cleft palate: - In this type of cleft, a cut is seen on the upper lip which occurs between mouth and nose. This is caused by inappropriate fusion of the upper lip with facial parts during fetus development. Unilateral cleft is the type of cleft occurs on one side of the lip while if there is cut on both side of the lip it is referred as bilateral cleft as seen in figure 2 below. A cleft lip detachment may be comprised of different types of the bones of the upper jaw and upper gum. This may extend from a minute notch in the gum to an entire disjunction of the gum into dis-join cuts.
2) Cleft palate without a cleft lip: - A cleft palate is a gap on the top of the mouth in which the two edges of the palate do not bind, or attach together around the 10th week of development in the fetus. The end of the palate towards the throat is termed the soft palate and the anterior towards the mouth is recognized as the hard palate. A cleft palate starts from a gap at the end of the soft palate to a closely entire division of the top of the mouth.

3) Combination of cleft lip and cleft palate.

There are some problems associations with a person born with these disorders.

1) Eating: - Eating can be a huge problem for an infant who is born with cleft palate. With a split or gap in the palate, food and liquids can flow from the mouth and penetrate the nose. Specifically created baby bottles and nipples that aid grip fluids moving downward toward the stomach are applicable. Babies with a cleft palate may require to wear a man-made palate to assist them feed correctly and affirm that they are ingesting sufficient nutrition until surgical treatment is offered. Kids with a cleft lip have fewer issues nourishing than those with a cleft palate. The baby with an unrepaired cleft palate has difficulties in sucking on a normal nipple and will usually need a particular nipple and bottle along with suitable method to eat.

2) Hearing: - Several babies with cleft palate are likely to the buildup of fluid in the middle ear or ear complications because of the malfunction of the Eustachian tube. This fluid buildup posterior in the eardrum can affect hearing loss. Hence, kids with cleft palate normally need small pressure equalization (PE) tubes applied in their eardrums to enable them to dry up the fluid and cure hearing. Kids with cleft palate should have their ears and hearing examined annually or every 6 months, and even more often if there is ear secretion or if a child seems to claim of having a complication of his/her hearing.

3) Speech: - babies with cleft lip or cleft palate may speech problems. These infants voices don't convey eloquently, and can sound nasal also the speech may be complex to recognize. Not all babies have these issues. Corrective surgery may improve these matters totally for several. It is stated that this problem is mostly seen in kids with cleft palate and lesser in cleft lip. Nearly 15%-20% with cleft palate may have speaking problems after subsequent remedy of the cleft palate. The prime issue is nasality or hyper-nasality. This occurs due to the palate that commonly splits the nose from the mouth for controlling sounds.

4) Dental problems: - babies with a cleft lip and palate usually have dental issues. “Small teeth, missing teeth, extra teeth or mispositioned teeth” (2) are disorders frequently seen in children with cleft palate or cleft lips.

It caused by two ways:-
1) **Genetic factors**
2) **Environmental factors**
**Genetics factors:** - includes various types of syndromes are described below

1) Van der Woude syndrome: - an autosomal dominant syndrome improvised by a cleft lip or cleft palate, distinctive cavities of the lower lips, or two. This disorder is commonly found in cleft palate and cleft lip. The class to which individuals who express the gene are influenced expansively differs, consecutive within families. “The gene for van der Woude syndrome has been localized to chromosome 1q32-q41” (9). Sometimes, it can be also found in the chromosome 1p34 (9). It is caused by mutation in the gene called IRF6 (9).

2) Siderius X-linked mental retardation: - mutation in the gene called PHF8 gene leads to Siderius type X-linked mental retardation (9). The locus of this disease is found in Xp11.2 (9). Since it found on X chromosome, it is X-linked disease. Along with mental retardation it also causes cleft palate in the individual.

3) Stickler Syndrome: - is genetic disorder associated with collagen inherited in autosomal dominance manner. Genes associated with this syndrome are COL2A1, COL9A1, COL11A1, and COL11A2 (9). Mutation in any one of the listed gene leads to soft cleft palate.

4) Loeys–Dietz syndrome: - this syndrome is related to the genes of connective tissue which could lead to cleft palate. It is also an autosomal dominant disease. The mutations in genes TGFBR1 and TGFBR2 leads to this syndrome (9).

5) Hardikar syndrome: - is the rarest syndrome related to cleft palate (9).

6) Patau syndrome: - also known as trisomy 13. It is not inherited in families but occurs during fertilization in either sperm or eggs. It leads to extra copy of chromosome 13 which leads to birth defects such as cleft palate or lips (9).

   Genetic disorder occurs due to change in a gene known as mutation. It also occurs when a child carries mutated gene from either or both parents because each parents gives 23 chromosomes as seen in figure below. Chromosomes are source of genetic material and information expressed in a child. Another genetic disorder occurs when a child inherit many genes which in combination cause genetic disorder. (5)

**Environmental factors**
Include drugs, viruses or toxins. In-take of less amount folic acid (vitamin B) leads to defects during fetus development in pregnant females. Also, medication during pregnancy cause defects in the fetus. “These medication drugs include anti-seizure or anti-convulsant medications, antibiotics, antidepressants, heart or blood pressure drugs acne medications comprises of Accutane, and methotrexate which are common for treating cancer” (10). Exposure of pregnant woman to viruses or toxin may lead to cleft palate in the fetus’ development. Also, when a pregnant woman smokes, consumes alcohol or tobacco, this may also cause defects in fetus development. Research states that when pregnant woman intake drug called depakote, could lead to the development of a cleft palate in her child (6).
The probability of cleft palate depends whether number of family members has cleft, if yes then there is more chance to occur. Also, it depends on gender, race, how closely an individual is related and type of palate family member has. Normally, the risk of re-occurrence of cleft palate is unique in the family. Unfortunately, there is no genetic testing available that can detect whether offspring has cleft palate or not, also of having probability to occur. “1 of every 700 infants” (7) is affected by a cleft lip and/or cleft palate. The probability of recurrence rates for cleft palate is seen in figure 3 clearly. For the parents whose one child already born with cleft palate, risk of having cleft palate for next child is 2-5% which means 2 to 5 chances in 100. If they are more than one person in the family with disorder then chances becomes 10-12 % for child to born with cleft defect. In other case, if a person has cleft disorder and only one with disorder in the family then chances of having cleft palate to child is 2-5%. If a person has closely relative who has cleft palate then chances increases to 10-12% for child to born with disorder. Finally, if there is sibling not affected by cleft disorder of a person, but that person has cleft disorder. Then chances of having a child to born with disorder are 1%. Chances of child increases to 5-6% to born with disorder, if closely relatives of parents have cleft disorder. The chances of re-occurrence in the family can be 50% if disorder is involved. In this case, genetic evaluation can help to analyze disorder.

Facts about Cleft damage-
It is the most common and visible birth defect observed in the children. It varies among races or ethnic groups as seen in table below (11)

<table>
<thead>
<tr>
<th>Ethnic groups</th>
<th>Per 1000 living birth</th>
</tr>
</thead>
<tbody>
<tr>
<td>Native Americans</td>
<td>3.6</td>
</tr>
<tr>
<td>Asians</td>
<td>2.0</td>
</tr>
</tbody>
</table>
Indians 1.5
Europeans ancestry 1.0
Africans 0.3

References:

Effects of Soft Palate Damage (SS)

Ear Infections:
The cleft palate also increases the risk of getting ear infections. This is because the air and fluid that normally passes through the tubes connecting the middle ear and the throat (Eustachian tubes), isn’t possible with a cleft palate. This will cause fluid and germs to become trapped behind the eardrum, and will eventually lead to ear infections. Hence, patients of soft palate need a special surgery to insert tubes into their ears just to drain fluids properly. If one doesn’t get this surgery done, and repeated ear infections occur, one could loose their sense of hearing.

Dental Problems/Speech/Feeding Problems:
When a baby is forming in the uterus, around the 6th – 10th weeks of the development, the baby’s bones and tissues of the upper jaw, nose and mouth fuse to form the roof of the mouth and upper lip. When this fusing process does not occur smoothly, the baby will be born with a condition called cleft palate. Usually, when there is a mistake in the fusing process, the baby’s upper teeth will too form unnaturally or miss some of its teeth. Hence, often leading to a baby to having dental cavities. Also, a baby while growing need to make frequent visits to the dentist to have regular check-ups, and have braces put into place by an Orthodontist. This is often a common problem found with babies with cleft palate. Cleft palate also will lead to speech and pronunciation problems. When speaking, the soft palate prevents air from going up the nose. With a cleft palate, this problem will be prevalent. The air will leak out through the nose when speaking. Hence, phonics will be a problem with this condition. When one swallows food or liquids, the tongue will press against the soft palate to prevent the liquid or solids being swallowed from heading into the nasal cavity. With a cleft palate, this is a problem, and babies...
often have problems just trying to drink milk. A newborn baby hence needs special feeding tools. Some of these tools include the Haberman Feeder made by Medela, Nuk Nipples made by Gerber, Pigeon nipples made by Respironics, and the Mead Johnson Cleft Palate Nurser. These specially made feeding supplies cost a little more than the usual supplies.

Tools That can be Used to feed infants born with Cleft Lip/Palate

Ross Nipple - This is a soft nipple shaped like a syringe that is usually used with the Haberman feeder. The syringe like nipple will facilitate a smooth continuous milk flow while decreasing the amount of air that could be sucked in. This is usually used for post-surgical feeding.

Cross Cut Nipple - This is a soft Nipple which has a X-shaped opening. This is done so that the flow of milk is only present when the baby squeezes the bottle and direct the milk flow past the cleft. Although this kind of nipple is sold in markets, one could easily take a razor and cut into a
nipple, and save costs. This nipple comes with the Mead Johnson Cleft Palate Nurser.

Mead Johnson Cleft Palate Nurser - The walls of this bottle is much softer and parents can help their babies with cleft drink out of this bottle by helping to squeeze the bottle. A drinking rhythm then could be established.

Haberman Feeder - Fluid will only flow with these bottle when the baby bites on the nipple. Flow rate could be adjusted from slow to medium to fast, and this could be located on the sides of the nipple. Parents can also help by squeezing the nipple. A one way valve also prevents the buildup of negative pressure.

Pigeon Nipples/Bottles - The pigeon nipple has a Y-shaped cut, and is a one way valve, and this helps to prevent the buildup of pressure. One side of the nipple is softer then the other side. This
is helpful when the baby uses his/her tongue to feed. The notch in the nipple must be aimed at the baby’s nose.

Social Problems:
An individual often born with a cleft palate can have this treated, but will have scars on their face for a long time. Children who have little understanding about this condition will tease or bully these individuals. This could lead to devastating psychological effects in these individuals. Often this could be a scarring experience for these kids who are recovering. These kids are often at a very tender and fast learning stage of their lives. Bullying them can grow to become an even more serious and dangerous mental health condition. Depression and other psychological effects can be an example. In third world countries, where there is little understanding about cleft palate, these individuals could be shunned as outcasts – leaving them to be isolated and ashamed of their facial birth defects.

Academic Problems:
As stated earlier, language and speech problems could hinder an individual with cleft palate to learn. Also, in a professional level, their pursuits to a certain type of career choices can be halted. For example one with a cleft palate would find it hard to be a professional singer or a lawyer where communication is of utmost importance. Also, from bullying and teasing, a child could be discouraged from learning and drop out from school. There are professional services to help out with this issue, but where these services lack, could lead to hard times for these individuals.

Professional Help Organizations:
Operation Smile:
This is a non-profit medical organization that was formed in 1982 by William P. Magee and Kathleen S. Magee. The goal of this organization is to collect charity in hopes of providing individuals enough funds for reconstructive surgery. Operation Smile also has over 600 student volunteer organizations to help raise awareness, funds and educate students about cleft palate. One such organization is located in Rutgers New Brunswick.

The Cleft Palate Foundation:
This is a non-profit organization which is dedicated to optimize the quality of life for individuals who are affected by cleft palate and cleft lip. They were founded in 1973 with the help of the American Cleft Palate-Craniofacial Association in 1973. Some of their goals are to advance the public’s knowledge of these conditions via research, spread awareness, and help individuals and their families deal with their craniofacial birth-defects. They also have a toll free number to help with this progress. One of their outstanding accomplishments are annual research grants to aid with the investigation into the causes and treatments of facial birth defects. They also offer college scholarships. They also offer scholarships to support nurse and orthodontic resident education.

Alliance for Smiles:
This is an organization that sends volunteer surgical teams to sites for missions that last two weeks. Each team consists of approximately 20 volunteer doctors and surgeons. This organization works side by side with local medical practitioners to exchange ideas on proper
medical techniques and procedures. They also provide follow-up care. They also establish and maintain permanent centers to.

*The Smile Train:*
This organization was co-founded in 1999 by Brian Mullaney and Charles Wang. Their mission is to provide free cleft surgery for poor children in developing countries, and to provide free cleft-related training for doctors and medical professionals. This organization proposed in early 2011 that they intend to merge with Operation Smile.

*Ameriface/cleftAdvocate:*
Ameriface was founded in 1991 to provide with educational and emotional support to patients of cleft lip and palate. In 2004, they partnered up with and merged with cleftAdvocate. They also strive to provide online support forums, volunteer staff and peer counselors to educate medical professionals about the needs of families, both educational and emotional.

*Smiley Faces Foundation/Institute of Reconstructive Plastic Surgery’s Cleft Lip and Palate Clinic:*
This is a nonprofit organization whose mission is to support the Institute of Reconstructive Plastic Surgery’s Cleft Lip and Palate Clinic located in New York University Langone Medical Center. They were founded in 2009 by Adam Bell. Their mission is to raise awareness and funds to assist the institute to provide proper treatment for cleft lip and palate in the United States.

*Interplast/Resurge:*
Donald Laub founded this organization in 1969, and is the first organization established to provide free reconstructive surgery in developing countries, mainly for children with cleft lip and palate. They began to organize surgical volunteer teams to Latin America, Asia and Africa. They then started to educate doctors in developing countries by providing directors to help with the resources like money, education and supplies.

*Smile Network International:*
This is a non-profit organization founded by David Valentini and his wife. They provide surgeries for cleft palate and lip for free. They estimated each surgery to cost around $500 per surgery. They also provide volunteer trips/missions to other developing countries.

**References**

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9. [www.smiletrain.org](http://www.smiletrain.org)
10. [www.smileyfacesny.com](http://www.smileyfacesny.com)
Different types of therapies and average costs of surgery (MM)

*Treatment for Cleft lip/palate:*

The Treatment for cleft palate repair can start in early childhood and can last till adulthood depending on the severity of the cleft. In most cases, the cleft palate repair requires surgical and non-surgical techniques to live a normal life. Surgery is the primary option for curing the defect but multiple surgeries are also required for complete cure of this defect. Generally, the surgery is carried out at particular ages as described below:

- **Age:** 6 week to 6 months – *Initial Surgery:* lip closure
- **Age:** 8 months to 18 months – *Surgery:* Cleft Palate Repair
- **Age:** 2 years to 18 years – *Additional Surgery:* Cleft Palate Repair
- **Age:** 8 years – *Bone grafting*

After surgery, some additional treatments will be needed for the correction of secondary problems, which involve speech, teeth, and hearing. Sometimes, the cleft palate is detected by the fetal ultrasound technique if it is severe enough.

*Types of Therapies:*

*Surgery:*

The Surgery is carried out based on the type of cleft palate defect. There are some common types of surgical techniques used for cleft palate. They are described below:

1. **Von Langenbeck Procedure:**

   Von Langenbeck started simple palatal closure. It is still used widely. The incision is made on the oral side of cleft edges. This technique is used for closing medium length defects in the cleft palate.

2. **Palatal lengthening - V-Y pushback:**

   Kilner and Wardill produced a technique for the palatal repair in 1937, which is known as V-Y pushback. It carried out by lateral incisions, bilateral flaps, closure of nasasl mucosa, fracture of hamulus and V-Y pushback palatal lengthening.

3. **Intravelar veloplasty:**

   This technique was designed to lengthen the palate and for the improvement of velopharyngeal function. But, no significant results were found.

4. **Double-opposing Z-plasties:**
Furlow had found the single palatal closure technique in 1986. It is comprised of double opposing Z-plasty by oral and nasal tissues of the body. The lateral relaxing incisions is not used. The cleft palate is closed by flaps little tented with some empty space.

5. Two-flap palatoplasty:

Bardach and Salyer individually corrected two-flap palatoplasty in order to achieve one common interest of the complete closure of the cleft and normal function of soft palate at the age of less than two months in children. The Speech therapy is required in some cases.

6. Velar closure - Delayed hard palate closure:

Schweckendiek invented this technique. During this technique the soft palate is closed in unilateral clefts and after three weeks the lip surgery is carried out. In the bilateral cleft, one side of lip is closed with primary veloplasty and after three weeks the other side is closed with the alveolar cleft.

Procedure:
The Surgery begins with the intravenous sedation and the anesthesia given to the child along with the required medications. The incision is made to both sides of cleft in order to make flaps of tissues, which are then stitched for closing the cleft. The incisions are closed by removable and absorbable sutures. There is enough length kept at the closing of the cleft, so that the normal speech, feeding and growth can be developed.

The Antibiotics and pain reliving medicines are given after the surgery. The movements of arm and hands are restricted in many cases of children to stop from touching the operated area. The patients are given only liquid by mouth or nothing from mouth but by IV fluid. The Oximetry of the patient is continuously watched for one day. Sharp edged toys and things are kept away from the patients.

In Utero repair:
The cleft palate in embryo is detected by the fetal ultrasound technique during pregnancy, if it is very severe. This technique is not fully developed, but research is going on this techniques application.
Tissue Engineering:
In Tissue Engineering, new tissues replace the infected tissues. These tissues are prepared using the stem cells. The new tissues can be used for generating bone in teeth ridge. This technique is also not fully developed, but research is going on this techniques application.

Non-Surgical Therapy:
The non-surgical therapy for cleft palate comprise of speech therapy. Sometimes, due to the secondary problems for teeth and speech occurs. They occur due to the repositioning of the palatine muscles, using of nasal flaps in the surgery, flap closures of hard palate and of alveolar cleft. The Speech therapy is required for the normal speech exhibition after surgery. After surgery, the nasal cavity do not close from the mouth which results in a condition called “velopharyngeal inadequacy”. This results in hypernastility and air comes out of nose while speaking and sounds like talking from nose. This velopharyngeal inadequacy occurs due to following factors which can overcome by speech therapies.

- Developmental Articulation and/or Phonology Problems
- Compensatory Articulation Errors
- Sound Distortions

Cost of treatment for Cleft lip/palate:
Cost of Surgery:
The children who are born with cleft palate defect are considered to have common birth defect. These birth defects are generally covered by insurance. An average cost of surgical treatment ranges from $5000 to $20,000 depending upon the severity of the cleft and case-to-case basis. The insurance companies cover mostly all the related expenses for the different therapies until the age of 21. The insurance covered patients have an average cost from $200 to $2000. The average cost roughly comprise of expenses including Hospital Room $5000, Pharmacy $500, IV Therapy $100, Operating Room $2500 and Anesthesia $300. Operation Smile is a non-profit organization and works globally for the patients with cleft lip/palate defects. They require a donation of $240 per patient to cover all the treatments.

Additional Costs:

Speech Therapy:
Some insurance companies are not providing the post non-surgical therapeutic expenses for the patients having cleft palate. The cleft palate patients need to get speech therapy which is sometimes covered by the insurance companies, by certain schools for free otherwise it costs up to $100 an hour.

Bone Grafting and Braces:
The children who have cleft palate in most cases require the teeth-bridge bone grafting at age of about eight. They also need braces at the age of 5 to 6 for their teeth. Usually, an insurance company does not cover this orthodontic care. The expense of this orthodontic care is estimated to be around $10,000.
Aftermath of surgery, and how life has changed. Survey of the Public opinion on how much they know about this, and case studies (RV)

The process of after surgery is quite as complex as there are many things that need to be adjusted and one has to get used to in terms of the environment, daily routine including diet and activity. At the time surgery is done there are stitches that are put in to fix the top of the mouth which would then allow the person to eat and talk properly through speech therapy. The process after surgery includes a process of helping the kid with the irritable sensation of touching the place where surgery is done or having no negative impacts on surgery by having padded restraints on the arm which would avoid the person to touch any part where the stitches would be present. The stitches could be dissolved or would have to be taken out within a period of time which would be five to seven days. If the surgery is done for cleft lip then there would be stitches at the lip and the nose which after surgery is done could swell up or cause bruising in that area. Also if the surgery is done on the cleft palate there could also be some possible swelling or blood drainage at the site of surgery. There are many other things such as medicines prescribed for when pain arises due to the surgery done and to avoid the irritation and feeling behind it. The surgery done may leave a scar that will fade over time but will not completely go away. Due to the surgery the person may feel little pain which can be cured with a non-aspirin medication.

There are steps taken after the surgery is done to ensure that the person is able to take proper intake of food and perform certain functions. Cleft lip is a process dealing with the outside of the face which is less involved. On the other hand if the surgery is done to the cleft palate then it is usually more involved as has to take care of more things inside the mouth and intake becomes difficult. In both the cases may it be with the cleft lip or cleft palate right after surgery the patient will be using intravenous catheter which is used as it is helpful to give fluids to the person until they can intake on their own sufficiently without any more problems. Many kids and infants after cleft palate surgery could have possible signs of nasal congestion because it is closely related to the where the palate is. These signs could possibly include mouth breathing, nasal snorting, and also may have decreased appetite. To cure these signs one may take medications prescribed by their doctor. To keep the surgery area with the incision clean one must use small amount of water after every meal or as needed.

In terms of diet it depends on the how the healing is after surgery but mostly one will be allowed bottle-feeding, breastfeeding or cup-feeding their child. The diet should consist of soft foods for seven to ten days after surgery so it could help the incision heal and make it better for later. This could vary depending if it is older infants or younger infants and this could make a difference on what type of soft foods could be included such as baby foods, popsicles yogurt, mashed potatoes and gelatin. Any food that could be hard should be avoided and that could include things such as hard candy, peanut butter, honey and things that kids like that could potentially be hard. Also one

References

must make sure that the child does not use a pacifier or straw as this could damage the surgical repair and possibly cause harm to the incision and the stitches. Next as this surgery is usually done to kids at young age of about eight to sixteen months there are some restrictions when it comes to activity right after surgery which include there should be no play with mouth toys after one to two weeks of surgery. One also has to make sure that there is no hard play or try to climb things as it could make it difficult for them as cause more irritation. After this there should be constant follow up with the surgeon making sure that all things are kept in mind that could cause harm to the surgery site.

Cleft lip and palate damage is a major concern among kids as its concerned with bringing a smile to one’s face and where it does not include any one’s fault but with these deformities there is a hesitation that kids may have when young or even as growing up to be able to get along with the groups and making sure they should also get all the rights they deserve. We took a survey on how well known people are about this and if they are in what way have they learned about this or seen it.

We took a survey of about 100 people and the results are as follows.

![Pie chart showing the results of the survey.](image)

Among about 48 percent have heard about it in terms of they know someone with this condition or they have heard it through friends and are familiar that way. There were also about 52 percent that were not aware of what this is or have never heard about it either. Despite the many
organizations and the many charities conducted for this condition, it is very astonishing that more than half of the people interviewed had no idea about what cleft lip and cleft palate is.

Case Studies: Ankur Radia
We studied a particular case, which is very close as it involves a team member’s relative. He was born with a hole in his soft cleft palate and conducted surgery at the age of fourteen months. We interviewed him and approached him about the after effects of surgery. He did not seem to recall a lot as he was too young being only fourteen months of age but he did say that his mom had to watch out the way she feed him and certain things had to be taken care of. He had conducted a surgery recently and to follow on the one he had to do when he was small. It required that there was a pharyngeal flap that had to be put in so it could block the airflow from the nasal cavity to flow in the mouth. For when he had this done there were stitches put in and certain restrictions or concerns where to be kept in mind. He was given painkiller to subside the pain, as there was some sort of pain due to agitation that was there. The recovery period was right after and lasted for about two weeks, where he was not allowed to intake hard foods and told only to intake liquids. At the time of the interview he also mentioned that even though he did not remember the recovery periods right after surgery as he was getting older he had to get speech therapy done which would improve and he would learn proper way of speaking as there would be changes in speech after his surgery. In his recovery phase where he was told not to have any hard foods, he remained on drinks and a particular drink was Ensure which was a nutrition drink which would almost be fulfilling as a whole meal which he consumed for a couple of weeks after surgery. He also said that he was told not to have any colored beverage such as anything red in particular as if something was wrong or if there was bleeding in the stitches it would be heard to distinguish if anything red was consumed. He is doing much better now after surgery and getting side-by-side speech therapy to better improve his speech and be able to speak and for others to understand him. He feels it was a better idea to get it done, as he is now able to better improve his speech and also interacts with people. He said that his family also believes that due this surgery he has been greatly impacted in a good way where now they do feel a difference in his speech over the years with speech therapy. He had the recent surgery done at St Peters Children hospital where he still continues to go for checkups and follow ups where there is a team of doctors that have him do tests and normal routine checkups to make sure he is improving and also have speech therapy continued so it could help him improve on speech.

Aaron Cook
Next case study is Aaron Cook who had a unilateral cleft lip and palate and it was detected before birth inside the his mother’s womb at the ultrasound where something was detected to go wrong and the person performing the ultrasound stood quiet as something was wrong. They knew he had a cleft lip but not sure at that time if palate too. When he was born he had a cleft palate too and then he was directed to the surgeon and went under the surgery for the cleft lip and more problems were solved but he had still a problem of cleft palate and this was making his feeding and other problems difficult and that is when they were directed by the same doctor to repair the cleft palate even at the age of four months as there was no harm. As soon as he got that done he was fine and able to feed properly and able to even get better nutrition as earlier he was losing weight but now he was actual gain the weight back and everything was getting normal. They received great support from the kings of daughter hospital at Norfolk that is part of the smiles organization, which has partnership Operation Smiles. They provided great support to this
family and then at the end of it everything turned out good. Now the family thanks the foundation and is very happy as Aaron has got new life and the after impacts were great because he can do things much easy now. He also has he grew up had found a speech therapist that took great interest to make his speech as best as possible

Destiny Folscher
Next Case study is Destiny Folscher and she had a unilateral cleft lip and cleft palate and she faced a lot of humiliation because she was not normal in the world where she was. She found elementary school very difficult and hard but then when she fixed her cleft lip when she was ten days old and then she also had to fix her palate and once it was done she felt great and amazing. Her life had changed completely she felt like a whole different person, as she was able to go out more and interact with people. So after surgery she had great recovery because she had surgery in the right frame of time and now when she goes out she is happy and likes to talk to people. She had great help for the Children’s hospital of King’s daughter in Norfolk and this was brought out by Smiles and brought to the public.

Grant Phillips
Another amazing story was Grant Phillips who was diagnosed with unilateral cleft lip and cleft palate and had to get surgery done not to cause more serious problems as it could lead to speech problems. He had many problems as to how, who and where will he find the answers to all his answers concerning the surgery. But as soon as he met Dr Magee who had also done surgery for the previous two cases was a great surgeon and within eighteen months Grant had great recovery and he was breastfeeding within twenty-four hours of surgery and also able to overcome the fact of itchiness and irritation as the scar was less visible and he could even eat better. So surgery has overall impacted him in a great way and he was now much better than before.

Michael
Next case is of Michael who was diagnosed with bilateral cleft lip and palate damage. It was very difficult for this family to address the problem as his mother had known this before his birth at seven months of pregnancy during the ultrasound she was shocked as everyone wants a normal baby and now something was wrong with her baby that she did not know what to do. But then every answer was solved with Doctor Magee assisting them and he got the surgery done fourteen days after birth and soon after he was much better feeling the best of his life and everything was back together for the family and this surgery proved to help them a lot. He was helped a lot with speech and also feeding, as they had to feed with syringe before which gradually went to bottle. So this was great moment that let Michael live as a normal child growing up.

Amy
Other case studies include from the Official Operation Smile facebook page where many have been helped such as Amy, Danila, and many others who were in need and once they did the surgery they are now much better and feel great to have got this done they find no after side effects as well as they are quite happy that they chose this as Amy especially did not have any money and they borrowed money and then came to do the surgery and after effects were great she was no longer ridiculed and made fun of but accepted in the community also now she is taking speech therapy to make her speech better and eventually get a better life. She is happy and
so is her family. So surgery is a great option to kids as they can change their lives for good and improve their oncoming life.

Some organizations that help with cleft lip and cleft palate are Smile: which is partnered with Operation Smile and then there is Cleft palate foundation and many other hospitals as well as other foundations that help with the great cause with the repair.

References

1. http://cleftline.org
4. www.cleft.org
5. www.operationsmile.org

The Service Project: Raising Awareness

Summary of Community Service Project:
Our service project focused on raising awareness on how plastic surgery could actually be a beneficial thing to children with cleft lip and cleft palate. We started our research by looking at various organizations and how they play a role in helping children with cleft palate and cleft lip. We approached the craniofacial head nurse at Saint Peters Hospital, New Brunswick and she led us to know more about how cleft palate and cleft lip are diagnosed and treated through the surgery. Some of the kids with cleft palate or cleft lip who goes to Saint Peters Hospital have such severe cleft palate or cleft lip that in such rare cases ever surgery is the only best option and should be done soon. When we met her she gave us brochures stating different aspect of cleft palate and cleft lip. They had a lot of information on anything in particular we would want to know about cleft lip and cleft palate such as information for parents also a guide to looking at feeding problems speech problems, as well as surgical issues and how that will be beneficial if surgery is done for the child. This Surgery has a great impact on the life of the person, as it changes person’s physical appearance and improves the social and mental ability and status. We interviewed Ankur Radia, a junior here at Rutgers Business School and brother of one of our team member. He had a hole in his palate and had gone through surgery for it at the age of fourteen months. We spoke to him recently on how has it affected him in any way and what challenges did he faced. He mentioned about that and could not recall all the problems back then because he was young. But, while growing up it affected him initially as foods were restricted and he was on just drinking an energy drink but as time went by he got used to it but he did mention that having that surgery helped him out and he was able to better communicate according to others as they were able to understand him. His family also thought that the surgery following speech therapy helped him a lot and helped his speech as well. We thank him as he helped us out in our study for cleft lip and cleft palate. The Operation smile at Rutgers holds stand-up comedy to raise money for the cleft palate and cleft lip by doing a comedy show where there are several comedians who performs and the audience pay for the tickets to support this event. It is basically volunteering, so anyone who wants to perform has to sign in and each of them get about five minutes to perform their act. The tickets for this show are about five dollars for Rutgers students and seven dollars for anyone else outside of the university. The tickets are
perfectly priced so that it can attract large audience and the larger the audience, the faster the awareness spreads. The show goes on for about an hour and half to two hours. As there are three judges they select ten out of the fifteen and then the audiences decide on which five out of them are better and at the end the three best win prizes. So, we decided to take part in this event and support as the money raised from this will go to Operation smile official and help out the kids that have either cleft palate or cleft lip. One of our group member, contacted Marcy Fromberg a Student Associate at Operation Smile International Headquarters, Norfolk, VA who helped her in creating one smile page on the official Operation smile website to increase awareness and raise fund for a single child with cleft lip or palate and also published an editorial including this web page as a link in a community newspaper to support this noble cause and for the fund raising.

Web page: http://www.support.operationsmile.org/goto/M.M


One Smile page for Fund Raising
Editorials

Nidhi Radia

My name is Nidhi Radia, I am a senior majoring in Biotechnology. I will graduate in January 2012. Before coming to Rutgers University, in January 2009, I was a student of Hudson Community College. My major in the community college was Biology. I was also part of honor society Phi Theta Kappa and Dean’s list.

I sent editorial to Hudson County Community college to publish in alumni monthly paper. The contact information of a person whom I sent is below

Plastic Surgery Restore Smiles

Have you ever seen a beautiful child who cannot eat or speak properly because there is a whole in his mouth? What problems are caused due to cleft palate disorder? What difficulties are faced by patients? Cleft lip makes it difficult for children to fit in with their peers. Have you ever thought how cleft palate is caused or if it can be corrected? Plastic surgery is beneficial to cleft palate patients.

Cleft palate is a common disorder seen in infants. It is related to soft palate. The soft palate is the soft tissue building the back and top part of the mouth. Muscle and connective tissue form soft palate. Since both muscle and connective are part of soft palate, it gives flexibility, mobility and support to the mouth.

Cleft palate is birth defect seen mostly in infants. During development of fetus sections of the face begin growing separately and then fuse together. The lip normally completes by 5 to 6 weeks later in the embryonic stage, along with the palate by 10 weeks. Correct development of the lips and palate is critical. This defect due to incomplete development is called cleft which means cut between two organs. Cleft lip and cleft palate is the fourth superior birth defect in the United States.

There are three main types of cleft:

1) Cleft lip without a cleft palate: - In this type of cleft, a cut is seen in the upper lip which occurs between mouth and nose. This is caused by inappropriate fusion of upper lip with facial parts during fetus development.

2) Cleft palate without a cleft lip: - A cleft palate is a gap on the top of the mouth in which the two edges of the palate do not bind, or attach together around the 10th week of development in the fetus.

3) Cleft lip and cleft palate together are a combination of cleft lip and cleft palate.
There are 4 main functions of the soft palate: articulation, speech, swallowing and velarization. It mainly deals with pronouncing syllables and food swallowing. The cleft palate damage is
associated with soft palate. There are certain problems associated with cleft palate disorder; which include eating, hearing, speech and dental problems.

The cleft palate is caused by either genetic or environmental factors. Genetic factors include various types of syndromes which occur mainly due to mutation in the genes. Environmental factors include exposure to drugs, viruses or toxins in the fetal stage. Exposure of pregnant women to viruses or toxins can also lead to cleft palate in the fetus’ development. Smoking, consumption of alcohol or other drugs, by pregnant women may also cause defects in fetus development.

Children with cleft palate damage face problems in different areas of life. Their condition affects them academically, professionally and socially. The problems start when one starts to speak and communicate in the society. Clefts affect children emotionally and psychologically as they face problems related to speech. This includes difficulties in pronouncing syllables and sentences which create problems for people to understand them clearly. Also, in school they can be the subject of ridicule from classmates. John had a hole in the palate. He went through surgery in infancy and took few sessions of speech therapy as recommended by his surgeon. When he started school he was not considered “normal” like other students. His classmates sometimes used to make fun of him by mimicking the way he used to mispronounce words. No one wanted to be his friend due to his disorder. Even in college same incidents occurred. Although, he had excelled in every class and maintained high GPA he did not get a job because of his speech problems. This resulted in depression.

When there is a problem, solution is always behind it. Solutions for cleft palate disorder are of two types. One is surgery and the other is speech therapy. The choice of treatment depends on age and type of defects. Surgery helps to fix the damage or fill the gap found in the disorder. This helps to give proper look to the damaged part. Speech therapy is based on the type of cleft palate defect and problems related to pronouncing syllables. This helps a patient to improve speech by teaching them techniques to pronounce syllable that they are not able to speak clearly. In this way, practicing and learning new techniques help them get better and perfect.

There are many institutions and organizations in the United States associated with cleft palate damage. They help patients by providing monetary and surgical support. One well-known organization is Operation Smile, a non-profit medical organization that collects charity to so that it can provide help patients for reconstructive surgery. One of its locations is at Rutgers University in New Brunswick.

The class of “Ethics in Science and society” taught by Dr. Julie Fagan at Rutgers University, New Brunswick, deals with selecting issues related to science and its impact on society. Under the guidance of Dr. Fagan, I, Nidhi Radia, along with three other Rutgers students Romal Vaidya, Sunke Sagar and Megha Shah will serve our community by spreading awareness about “The upside of plastic surgery.” We will participate in stand-up comedy organized by Operation Smile organization at Rutgers University to raise funds. We might also volunteer at Saint Peter’s Hospital.

Solutions such as surgery and speech therapy give new lives to patients. Surgery helps to reconstruct damage part of the body and results in proper shape and appearance; while speech
therapy aids to improve communication skills by practicing various techniques taught by speech therapists. This helps give courage, confidence and self-esteem to patients, and also motivates them to improve their professional and academic lives. They can live freely in the society without being mocked. Thus, it gives patient rebirth and leads to normal life with a smile. If it gives one person to smile then plastic surgery cannot be considered disadvantageous?

Sunkesula Sagar:

Cleft soft palate and cleft lip is a growing concern throughout the planet. The incidence of a newborn getting a cleft soft palate and cleft lip increases with daily activities that a pregnant mother does. Smoking and taking drugs increases the changes of a newborn getting this condition. What I find surprising is that there are over-the-counter medications now available that can cause a pregnant mother to give birth to a newborn with cleft palate or cleft lip. Some examples of these types of medications are anti-seizure or anti-convulsant medications, acne medications that contain Isotretinoin such as Accutane and Methotrexate that is a drug commonly used for treating cancer and arthritis. I call for the urge to understand why there are such drugs out there that can potentially affect a newborn.

The social, academic and professional impacts on a person born with cleft palate/lip are toll taking. After having interviewed a friend of mine, he tells me all about his experiences.

Socially, as he grew up, he had a hard time making friends. He was made fun of and bullied.

Psychologically, he was having a hard time to deal with. Self-confidence was not something he learnt quickly. Being a business major, self-confidence, and charisma is something he must be natural at. His cleft palate stops him from pursuing his goals. At an academic level, all the lack of self-confidence stops him from participating in class.

Although there are multiple organizations that advocate and support the cause to help people born with soft cleft palate/lip, a brief survey proved that less then half of randomly picked public knew what this condition was. My intention is to spread awareness to the public to know what this condition is, so that people like this friend of mine wouldn’t have to go through the torment of bullying, and difficulties in pursuing his/her career of choice.

Thank you,
Sunke Sagar

Megha Master

Title: Donate a SMILE

Dear Editor,
Smile is a symbol of innocent emotion. It has amazing power to share happiness and communicate without words. When we smile, did we ever take a moment to think about those who have defects like Cleft Lip/Palate? Can anyone imagine himself with Cleft Lip/Palate, it would be heart throbbing and no one would ever even wish to think like that.

The people with Cleft Lip/Palate from early childhood suffer not only because of their physical deformity but emotional, social and mental conflicts. They always see themselves from the eyes of other people and what they think of them. Since childhood, these children face difficulties in swallowing, breathing, eating, pronunciations, speech problems. Gradually, this defect separates them from the rest of the world as soon as they start understanding and realizing. Some of them face Academic impacts and remain uneducated because they think that other kids might make fun of them which is followed by social and professional impacts during later stage in life.

In America, the insurance company’s generally covers the medical expenses of kids with cleft lip/palate. Whereas, in some undeveloped countries or developing countries which are not so fortunate of having such medical laws and insurance benefits the children with cleft lip/palate suffers lifetime difficulties. On an average, medical expense of a single child cost from $5,000 to $20,000 including surgeries and therapies depending upon severity of the cleft and case to case basis. Operation Smile is non-profit help organization and works for children with cleft lip/palate worldwide. Operation smile ask for a donation of $240 to cover all the expenses of a single child.

Our life is gift of God; we should thank him in each breath for having a normal life. Let us join and contribute to this noble cause initiated by Operation Smile for creating a smile throughout the world. As a reason of thank you to God for our smile, please kindly donate at the below given website which can give a smile to someone who doesn’t have ability and fortune to smile.

http://support.operationsmile.org/goto/M.M

Thankyou,
Megha Master

Romal Vaidya

Hello my name is Romal P. Vaidya and I am a Senior majoring in Biological Sciences and minoring in Public Health at the School of Environmental and Biological Sciences graduating in January 2012. The purpose of this submission is that I am a student at this university taking a junior senior colloquium class which is Ethics in Science. In this class we are to work in groups on a project for the whole semester and raise awareness by also doing a community service project. Our topic that we have chosen is Soft cleft lip and palate damage and how plastic surgery can be a benefit and help many infants and bring a smile on their face. As part of the project we are to send an editorial to the place of our choice and bring out awareness. So I have chosen to send it to the targum. So below is the editorial. Please take a look and consider for publication.
Cleft palate damage is common disorder among infants which is detected at birth or even before birth. The soft palate is at the back of the mouth with soft tissue and it is used for many functions such as speech, articulation, swallowing and velarization which are the way words are pronounced. What is meant by soft cleft palate damage is that there is a break between two parts on the edges and they do not meet as they should be joined.

There can be three types of cleft. One is where there is cleft lip but no cleft palate in this case there is a cut in the lip that occurs between the nose and the mouth, within this there are two types unilateral cleft lip which cuts only one side or bilateral which cuts on both sides. Then there is cleft palate without cleft lip where there is not cut on the lip but there is a break or gap in the back of the mouth where the two edges of the soft palate meet. Last there is cleft palate and cleft lip where both the top ideas mentioned are combined in together and where more concern needs to be taken and will require two surgeries as they have to be done separately.

Infants with this disorder may encounter many problems such as eating, hearing, speech. Cleft lip and Cleft palate may have some genetic implications that may be involved. Also feeding the child becomes a major concern as the child has to intake of milk about every two hours and various feeding bottles are used depending on which one applicable to their need. Another problem is speech which may not come in as a problem in the beginning but later on when the child starts to interact and they may need to enroll in speech therapy during this as it will shape the way they speak. There may be many sessions of speech therapy which will carry on until the infant is older and more understandable. Other problems include academic and social impacts on the individual.

But to every problem there is a solution in this case which is by plastic surgery also best known as cleft repair process which is done at three months in general for cleft lip and for cleft palate done at about a year old or a little bit earlier or later depending on the situation at the time. This is easily solved by surgery as they fix the proportion of the lip and the palate inside the mouth, it also may include the nose as certain bones and tissue may be needed to move around to give a proper look. The cost of surgery cost about 5000 dollars as a whole with giving different proportion to pre surgical as well as post surgical options present.

There are many different organizations around the United States that help out with providing surgical treatments as well as money by having donations and the webpage for Operation Smile a well known organization tends to estimate a cost for full surgery could be fulfilled by 240 dollars and partial includes 120 dollars. There is also an organization for Operation Smile here at Rutgers University which helps for this cause by arranging events that could possibly raise money and would be able to donate to Operation Smile.

The results of surgery are great and the recovery is fabulous as after surgery there are not many complications unless there is also a syndrome associated along with the cleft lip or palate but in most cases everything is fine and the patient is let home that same day for cleft lip as the surgery is the morning and the patient is discharged by the evening. For the cleft palate the patient is at
the hospital for three days after the surgery as it has to be seen that aftermath for the palate is okay and not further action is needed. Then speech therapy is started and the patient has to stay in contact with a whole team of doctors in the different areas to make sure everything is okay.

So all in all if the question is asked is plastic surgery really required or is it a solution to smile? Yes in cases as such where it could change a person’s life by a simple smile and make them more acceptable and not denying in today’s society where they would be able to interact with all and be able to lead a normal life and not ignored in society.