**MPH Practicum Experience:** 

## Partner for Surgery

#### **Assessment and Recommendations for the**

## **Targeted Infant Nutrition Project**

Antigua, Guatemala Summer 2011



Final Report September 2011

Kristen Mallory MPH Candidate

The Ohio State University College of Public Health

#### **Table of Contents:**

I. Introduction	pg. 3-4
II. Acknowledgements	pg. 5-6
III. Brief Background of Partner for Surgery	pg. 7-8
IV. Goals of Practicum	pg. 9
V. Time line of Activities	pg. 10-11
VI. Methods	pg. 12-14
VII. Results/Findings	pg. 15-35
1. Literature Review       pg. 16         2. Goals of the TINP       pg. 17-18         3. Structure of the TINP       pg. 18-21         4. Budget       pg. 21-22         5. Current Demographics of the TINP       pg. 22-24         6. Satisfactions of Parents       pg. 24         7. Milk Forumula       pg. 25-26         8. Looking for Government support       pg. 26-31         9. Other Organizations working in the felid       pg. 32         10. Midwives project       pg. 32-35	
VIII. Conclusion/Recommendations	pg. 36-39
X. Works Cited	pg. 40
XI. Annex (Other products created by Kristen Mallory)	pg. 41
1. Logic Model for the TINP	
2. Revised Spread Sheet of TINP participant weight gain	
3. Interview Template for Parents of the TINP (Spanish and English)	
4. Interview Template Health Centers and the Health Department (Spanish a	and English)
5. Book of Charlas for promoters to use at missions (SPANISH)	
6. Training with the midwives (SPANISH)	
7. Spread sheet of Results from Parent of TINP Interviews	
8. Kristen's Health Talk: "How to give a Charla" (SPANISH)	
9. Kristen's Health Talk "About the nutrition project" (SPANISH)	
10. Check off sheet for the midwives to track birth defects	
11. Contact for possible partnerships Spread Sheet	
12. Success Story from the TINP	
13. Newsletter stories of patients from San Juan Faces of Hope Mission	
14.2010 Annual Report from the Ministry of Health in the Department Alta Guatemala) SPANISH	VeraPaz (generated by public health officials in

15.Triage/TINP entrance form (SPANISH)

## I. Introduction:



Partner for Surgery pick up truck headed to a triage mission Alta Verapaz, Guatemala



Guatemalan Flag



Guatemala is located in Central America under Mexico

Hello my name is Kristen Mallory. I am a Masters of Public Health student at The Ohio State University in the division of Health Behavior and Health Promotion with a specialization in Global Health. I completed my Practicum requirement by working with the Non-profit organization, *Partner for Surgery*, in Guatemala during summer 2011.

My previous international experience was through serving in the Peace Corps in Ecuador as a Community Health volunteer for three years. This experience inspired me to pursue a Master's degree in Public Health. My interests are in development, Latin America, and community health education. I wanted to intern with an organization where I could get experience in these areas. By chance I received a job posting from a friend about *Partner for Surgery*. I began to research their work and was very impressed. I contacted the country director in Guatemala in the winter of my first year as an MPH student. I was graciously offered an invitation to intern with the organization for the summer of 2011. I was told that they had a project that focused on nutrition for children with cleft lip and palate. They wanted me to assess the program and make recommendations for improvements given that it is in the position to grow.

This trip and experience was made possible by the R25 International Practicum grant. Without the help of this grant this lifetime experience would never have been possible. I left Columbus, Ohio on the morning of June 28, 2011 to begin a 10 week Practicum with *Partner for Surgery* in Guatemala. I had no idea at that time how my life would be changed by this opportunity. I was not prepared for the abundance of culture and life exploding from this small Central American country. Poverty and extreme health disparities were very apparent and eye opening. The people of *Partner for Surgery* and of Guatemala not only gave me the opportunity to apply my public health skills first hand in a field environment but also inspired me and motivated me to continue to pursue a career in this field.

The following report is a summary of what I learned and accomplished this summer. First I provide a background on *Partner for Surgery*. Next, are the specific roles and goals for the practicum, the activities that were done to accomplish these goals, and the results and conclusions. I hope that the results and conclusion of this report will be helpful and serve a purpose for *Partner for Surgery* and the future of the Targeted Infant Nutrition Project.



## II. Acknowledgements:



I would like to first and foremost, thank the Health Sciences Center for Global Health for making global health a priority on the Ohio State Campus and supporting students that are passionate about incorporating global health into their health service careers. Without the R 25 International Practicum Grant this trip would have never been possible.

I would like to thank the Ohio State University College of Public Health, in particular my academic advisor, Dr. Shelley Francis, who served as a mentor to me before and during the practicum. Her international experience along with approachability and excitement in the field has been integral in my studies and practicum thus far at OSU.

I want to give a special thanks to *Partner for Surgery* (PfS) for accepting their first, of hopefully more to come, MPH interns to work with them for this practicum experience. It was truly an honor. I would like to thank Frank Peterson, the co-founder and president of PfS for giving me responsibility and believing in me. He is the heart of PfS and having the opportunity to work alongside him in the triage mission was enjoyable and inspiring. Lindsay Coker, the in country director of PfS, who served as my direct supervisor and preceptor was extremely influential in my career development. Lindsay was my mentor through the 10 weeks. She helped me to ask the right questions and was always there to support me. I appreciated her constructive feedback and enthusiasm for the mission.

I was motivated and humbled by my co-workers: Fife Bently, Dr. Oscar Austurias, Silvia Eugenia Macario, Maura Cavanaugh, Paty Arriaza, and Marta Gomez who are knowledgeable and put their heart into their work for the people of Guatemala every day.

The real success for PfS comes from the health promoters, 20 who are active. Getting to know them and work with them was one of the most rewarding parts of my practicum experience. I have never met people so devoted and selfless. They are the ones who stay up all night with the patients during a mission and travel by foot to some of the most remote villages looking for patients. Without their tireless efforts PfS would not be able to complete their mission. I learned the Guatemalan culture from the health promoters, and was given insight into new ways to reach the people of Guatemala and our health goals.



## III. Background on the

Organization:









Partner for Surgery (PfS) officially became a non-profit 501(c) (3) in 2001. It began as a result of Ted Peterson's Peace Corps experience in a rural indigenous village in Guatemala. Through Ted's 2 years of service in this rural impoverished area he noticed the prevalence of people failing to thrive due to an ailment that could be corrected by a routine surgery. His father Frank Peterson who had visited several times was compelled to help. The organization started out very grassroots in nature with Frank and Todd looking for patients out of the back of a pickup truck, but it has grown in the past 10 years. Since 2001, Partner for Surgery has provided medical care and education to more than 25,000 and facilitated surgery for over 5,000 Guatemalans.

The majority of their patients, 49%, need General surgery, followed by 21% who receive Gynecology, 20% in need of Plastic/Reconstructive surgery and 10% ENT, neurology and urology type surgeries.

#### The mission of *Partner for Surgery* is:

"To serve as a bridge between patients in need of surgical care in remote communities and the international volunteer triage and surgical teams that come to Guatemala to help the impoverished." And also "To educate and empower rural Guatemalans to initiate and advocate for vital health care services on their own behalf." This mission shows PfS's commitment to sustainability and a dedication to public health in Guatemala.

Partner for Surgery currently has 30 employed Guatemalan health promoters who live and work in the communities. Their job is to help find patients in the areas where they work and act as patient navigators. Because the majority of indigenous Guatemalans residing in rural regions speak one of the 21 Mayan languages other than Spanish these promoters are integral in translating and assisting the patients who have often never left their villages to go to the city to receive surgery. In order to make PfS sustainable they assisted Guatemalans in creating their own entity Companero en Salud (Partner in Health) this has changed over the years to be called Asociacion de Companero para Cirugia (ACPC). The health promoters along with Guatemalan staff that work in the central office in Antigua, Guatemala are all technically employed by ACPC and collaborate with PfS. This group is gaining responsibility and autonomy with the goal to eventually remove the PfS presence in Guatemala and limit it to fundraising in the United States.

In 2009 the PfS Targeted Infant Nutrition Program (TINP) was created. This project was in attempt to battle the extremely high rates of malnutrition among babies with cleft lip and or palate. The first goal was to save these children's lives from premature death, the second was to perform corrective lip and palate surgeries. A child that is undernourished and underweight would not be able to survive one of these types of surgeries nor would the medical teams risk operating on them. For this reason PfS is working to provide alimentation to these children in order to prepare them for surgery. This program although ambitious and with great motives, lacked organization and systemization. For this reason, PfS wanted me to focus on this program from a Public Health perspective to organize the goals and processes, in order to make the program more efficient and sustainable. The following work is what I found in regards to the TINP.

## IV. Goals of the Practicum:

(developed with the assistance of Lindsay Coker and Fife Bently)



#### 1. TINP part 1: Milk Distribution and Education

- a. Define goals and objectives for the project
- b. Determine indicators. How will success be measured
- c. Define protocols (activities and processes)
- d. Access budget to see if things can be done more efficiently
- e. External statistics about children with cleft lip and palate
  - i. Talk with the Health Department *Area de Salud* along with other national organizations that are working in Infant health to get some stats and create partnerships to ensure sustainability.
  - ii. Research the organizations that are working with cleft lip/palate children to generate statistics and/or share best practices.

#### f. Internal statistics

- i. Project stats, how many kids, average age, average time in project, number of kids who graduate each year, etc.
- ii. Interview parents in the project (satisfaction)
- iii. Interviews/conversations with promoters (satisfaction/suggestions)
- g. Continuing Education for Promoters
  - i. Train promoters on "how to give a health workshop charla"
  - ii. Develop a manual for the promoters to use in their educational talks
  - iii. Assist/coach in giving charlas at medical missions

#### 2. TINP part 2: Help implement the new midwife pilot project

- a. Meet with midwives for statistics and to share ideas
- b. Develop check off sheet with pictures for the midwives to record birth defects
- c. Organize a breast pump training, and design the intervention
- d. Speak with the division of the government that trains midwives to figure out the possibility for this project and its growth to other regions in the country
- 3. Create a final report that completes these objectives in writing along with providing an overview with recommendations for the TINP

## V. Timeline of Events:

Dates	Activities	Final Products
Week 1:	-Reading over all of the TINP documents and	-Understanding of the Organization and
June 28,29	office policies	the TINP
	-meetings with Lindsay on overview of	
	organization and my project.	
Week 2:	-Organize the weight data for children in	- Revised Weight Spread Sheet for
July 4-8	the project	children in the TINP
	-Look for an example of success in the TINP	- Success story from the TINP
	-Meeting with Fife and Lindsay to	-Written timeline with goals and
	determine goals of the internship	deadlines for the summer
	-Scheduling with Fife	
	- Timeline/Goals for the summer	
Week 3:	-Prepare 2 workshops for the Staff Meeting	-Two presentations ready on the
July 11-14	-Introduction about the Nutrition Project	Wednesday before the meeting to
	(combo with Dr. Oscar)	be checked by Fife and Lindsay
	-How to give a health charla	-An outline of the topics to be
	-Prepare breakout session with TINP	covered in the break out session
	promoters to determine goals and	-Tentative goals and objectives to go
	objective along with concerns in the	over with the promoters
	project	-c harla book completed and copies
	-Compile a book of 10 basic health charlas to	made for all of the promoters
	give to each of the promoters	·
Weekend 3:	-Facilitate the 2 workshops	-A formed relationship with the
July 15- 17	-Facilitate a break out session for TINP	promoters that I will be working with.
	Promoters	-Ideas and suggestions from the
	-Participate in the Meeting's activities	promoters in regards to the
		objectives/goals of TINP
		- Promoters will gain new knowledge
		and motivation to continue their
		work in the TINP and implement
		educational charlas
		-Each promoter gave one of the charlas
		from the book they received in order
		to practice.
Week 4:	- Develop an interview for the parents of the	- Finalize interview for parents to
July 18-21	nutrition project.	administer during home visits
	- Develop an interview for the Area de Salud	-Finalize interview and what we want to
	-Put together goals and indicators (based on	know from Area de Salud
	break out session with promoters)	-Revised Goals and Objectives for the
	-Develop form for midwives to identify birth	TINP
	defects (with pictures)	-Finalize form for midwives
	-Put together contact list of potential	
	partnerships for the TINP	
	<u>'</u>	
Week 5:	-Travel with Fife to see the home visits for the	-Knowledge of the process involved in
July 25-29	TINP and visit the Areas de Salud	delivering milk and educating parents
,	-Administer interviews with the parents from	-Statistics and other useful information
	the TINP and the Area de Salud	from the Area de Salud
	-Develop plan for the meeting with the	(3 different interviews completed)
	midwives	-Comments and suggestions from the
	1	escite and subpestions from the

Weekend 5:	Leave for the San Juan Mission and help orient	parents participating in the TINP (4 interviews completed) -Tentative plan for midwives meeting -Plan for the week	
July 30,31 Week 6: August 1-5	the medical team  Mission at San Juan -Help translate -Interview parents -Develop plan and help promoters give charlas -Talk with SJ health post to see what kinds of stats they have on the area -Interview children and their parents for newsletter stories	-Each promoter will facilitate at least one charla throughout the week that I will be able to watch and give feedback afterwards -Feedback from parents (6 interviews) -Help for the medical team -Information for children already in the program -Interviewed three different families for the newsletter	
Week 7: August 8-11	-Work on processes and protocols -Look at budget, how could things be more efficient and economical -Determine success indicators -Help plan and give a health charla in the "casa de fe" during the Faces of Hope mission in Obras -write stories for the newsletter	-Draft of protocols and processes -Draft of indicators -observations about the budget -Completed charla on dental hygiene with a ACPC health promoter and Faces of Hope volunteersubmit 2 potential stories for the PfS newsletter (both were featured)	
Week 8: August 16-19	-Prepare for Triage mission -Get in contact with Smile train, USAID, other national and international organizations in the area of infant health	-Information on potential partners -Possible stats	
Week 9: August 21-28	Triage Mission -translate -interview parents and health workers -work with promoters on their charlas -collect stats from the health centers	-Each promoter will facilitate at least one charla throughout the week that I will be able to watch and give feedback afterwards -Feedback from parents -Help for the medical team	
Week 9: (August 25 <sup>th</sup> )	Assist Comadronas monthly meeting with Mayra (ACPC promoter) -Introduce ourselves -Charla (Nutrition for children after 6 months of life) -Introduce the TINP to the group -collection of data from previous month -Make plan to continue collecting data -Figure out who organizes the trainings	-Meeting Minutes -Better idea of how we will collaborate -Trainings for the Comadronas	
Week 10: August 29- Sept. 2	Wrap up in the office Organize and analyze data/results	Turn in final goals, objectives, indicators, protocols, and budget recommendations	
End of September	Work on final report	Final Practicum report sent to Partner for Surgery	

## VI. Methods:





Following the previously mentioned timeline, I was able to complete the goals of the internship. First, I analyzed all of the existing documents that had been created by a variety of *Partner for Surgery* staff over the two years of the TINP's existence. With these documents I was able to get an idea of the work that had been done, and was being done, in the field along with the goals that PfS was working to achieve.

With this information and suggestions from current PfS staff, I was able to create new documents that organized and consolidated the project's information. (see results)

I developed a logic model (ANNEX 1) to organize my thoughts and did a brief literature review of the problem to get a better idea of the public health issue that the TINP was trying to tackle.

I designed a new way of tracking the infant's weight in order to see progress more clearly. This spread sheet can be found in ANNEX 2. With this information, I determined how many children had gone through the whole process since 2009, along with how many children are in the project currently. I was able to determine the demographics of the group of participants and see how quickly they were gaining weight as a result of the TINP.

The other areas of my work were done in field in order to get a firsthand look at the activities that are being implemented and how they are being implemented:

- 10 formal interviews with parents of children in the program (satisfaction interviews) the majority of
  these interviews needed to be done with a translator because the majority of the participating families
  spoke one of the 21 recognized Mayan languages. The interview template can be found in
  ANNEX 3.
- 3 formal interviews with governmental health workers in the area (generation of statistics, along with understanding of the national health system) these interviews were done with the assistance of Fife Bently in the Department of Alta Verapaz. The interview template can be found in ANNEX 4.
- 3 informal interviews with midwives and one of the midwives' coordinators in order to obtain a better understanding of the midwife system in rural Guatemalan and possibilities for collaboration with the TINP
- Informal discussions with ACPC health promoters working on the project, specifically Mayra Chen, Julio Chen and Aurelio Cordova to get an idea of the activities and anecdotal experiences in regards to the TINP.
- 4 family visits (observations of the houses and families involved in the TINP) to get an idea of the context in which participants are living.

I worked in health education with the ACPC promoters by compiling and editing a book of informal health education talks that can be replicated by the health promoters during medical missions and included in the TINP. I trained the promoters on how to give these health talks and facilitate a workshop in which they practiced giving one of the talks (see workshop: ANNEX 8). I also was able to help the promoters plan and facilitate these talks during the two medical missions that I assisted. I monitored 5 different health talks given to at least 20 participants. I was able to motivate the promoters and give them feedback. The revised book of health talks can be found in ANNEX 5

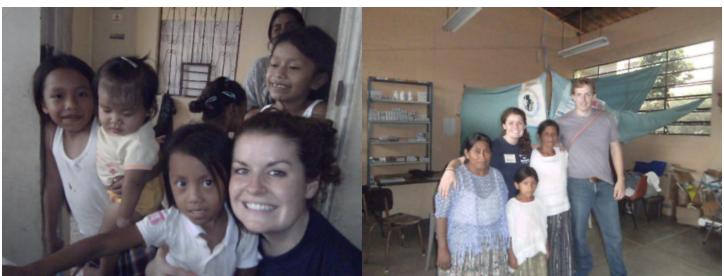
I also planned and co-facilitated a nutrition workshop for a group of 20 midwives. With this group I shared knowledge about nutrition for children over 6 months of age along with background on the TINP see ANNEX 6 for full training. This experience also served as observational and anecdotal data collection about midwives role in the Guatemalan regions that the TINP is currently serving. I developed a check off sheet for the midwives to identify birth defects and begin to

generate statistics of incidence in the births that they attend. This was part of the pilot project proposed by PfS to include midwives in the TINP.

The other documents that are found in this report were done by interviews, conversations, and internet searches. Although my main focus was the TINP, I also participated in writing patient stories for the PfS newsletter, translating, and making contacts and connections for the project's future growth.

## VII. Results/Finding:





#### 1. Preliminary Literature Review:

Cleft lip *cheiloschisis* and cleft palate *palatoschisis* are two of the most common congenital anomalies or birth defects that affect the cranium and facial region in humans. This is caused by abnormal facial formation during gestation. A cleft occurs when the tissue of the upper lip or the hard palate do not come together before birth. A cleft means an opening or fissure in a tissue. It is estimated that on an international level between 1 and 700 and 1 in 1000 births have a cleft lip or palate. Rates differ from country to country in the United States the incidence is 1 in every 600 births. In developing countries there seems to be a higher incidence of cleft births (Tighe, 2011).

Cleft lips and palates are said to be multifactorial. A known cause is not clear. Genetic factors and environmental factors play into effect. Studies have shown that there is a correlation with clefts and exposure to toxins during pregnancy such as smoking, alcohol, therapeutic agents (Phenytoin) and the nutritional status of the mother. Some studies have shown a relationship between clefts and Folic Acid deficiency in mothers (Wyszyniski, 1996).

Children born with clefts suffer an array of negative health consequences, such as frequent ear infections, respiratory infections, speech and language difficulties and feeding issues. Babies with clefts often times are unable to latch on from birth, this in turn causes a mother's milk to "dry up" which means the mother is unable to produce breast milk. Inability to breastfeed creates implications, especially for mothers living in low Socioeconomic Status (SES) contexts who are unable to afford alternative formulas. Babies with clefts who are able to latch on often have a difficult time sucking making them tire quickly while breastfeeding. Many times, infants with clefts are underweight and malnourished due to the barriers against them for breast feeding (CLAPA, 2010). Malnutrition early on in life has serious negative developmental consequences later on in life (USAID, 2010).

The most effective solution for cleft lip and palate is reconstructive plastic surgeries before the first year of life (ASPS, 2011). *Partner for Surgery* has connections with a number of surgical teams that come down each year and offer these services to Guatemalan children identified by *Partner for Surgery*. According to the American Society of Plastic Surgeons a cleft lip can be operated on after 10 weeks and palate between 9-18 months of age.

In Guatemala, many international organizations such as Face of Hope and Smile Train come every year to operate on children with cleft lip and/or palate. They have certain age and weight requirements to make sure surgeries are safe. Although the literature is very limited on incidence and prevalence rates of clefts in Guatemala, there seems to be a large number in certain regions for example, Alta Verapaz. The cases are under reported and need to be better recorded. One of PfS's goals is to obtain better statistics on this condition.

Before the surgery, in order to make sure the infant is growing adequately, it is important to concentrate on feeding techniques. *Partner for Surgery* is providing families with formula and squeezable bottles. They are also considering the use of breast pumps in order to prevent infant mortality and prepare infants for surgeries.

**Problem**: Many infants are coming to the PfS triage missions and are not able to breastfeed due to their cleft lip and/ or palate. These children that can benefit greatly from surgery (that is being provided) are ineligible due to low body weight and malnutrition.

These children come from poor, isolated regions that have no access to health care.

Barriers: Do not speak Spanish, Do not have the resources to pay for health services or travel to the services, Cultural barriers-fear of western medicine, Machismo, Cannot purchase milk, do not know how to prepare milk formula.

**Solution: Targeted Infant Nutrition Program (TINP)** 

#### 2. Revised Program Goals

**Overall Goal:** To prepare infants from the poverty stricken rural regions of Guatemala who are eligible for reconstructive cleft lip and/or palate surgery by helping them get to a healthy weight for surgery.

Evaluation: (Quantitative) Count how many children graduate through the program with both operations

(**Process**) **Objective 1:** Identify children with cleft lip and/or palate in the communities as early as possible to see if they are eligible to be part of the project.

Evaluation: (Quantitative) The age of children who enter the program, the number of infants with clefts that the midwives identify

**(Learning) Objective 2:** Provide enrolled families with education or training to increase knowledge of the importance of reconstructive surgery

Evaluation: (Qualitative) Through educational talks and house visits (evaluated by promoter) Participant interviews done by PfS staff during the medical missions to access the families attitudes and knowledge about the surgeries. (This is not currently being implemented)

(Process) Objective 3: Provide all enrolled families with access to XXX amount of milk each month

Nan 1-4 cans (for babies less than 6 months old)

Nan 2-4 cans (babies 6 months-1 year)

Nido- 1 bag (Children > 1year old)

\*These are the quantities that are currently being distributed, further on in the report are a plan To cut costs on milk and reduce the amount delivered each month.

Evaluation: (Quantitative) monthly reports from the promoters with the signature (thumb print) Of the families confirming that they received the formula and the health talk.

(Learning) Objective 4: Train all families on how to correctly use the bottles and prepare the formula after (1) brief training.

Evaluation: (Qualitative) promoters can check this knowledge and ability of the family during the Monthly visits. Occasionally a PfS staff member should conduct an interview that requires the family to demonstrate the behavior

(Process) Objective 5: All the children in the program will have their weight and height measured by the closest health center on the same day each month.

Evaluation: (Quantitative) the family must show the filled out health card (cardnet) with the weight listed and date.

• The Medical Director would like to change this process. The PfS Health promoter will have to weigh and measure the height of each child each month, on the same week each month. We want families to continue to take their child to the health centers to keep them from getting sick.

(Outcome) Objective 6: All children in the program will gain weight each month.

Evaluation: (Quantitative) Health promoter delivers reports each month to the PfS office that have all of the children's weight and health status along with the day that they were visited. PfS will enter the monthly weights into the new spread sheet and be able to quickly determine if the children are gaining weight.

**Long term goal:** secure funding to allow more children to enter the program and enter the children the earliest possible to avoid long term cognitive/development issues.

Evaluation: (Quantitative) counts of children in the project, along with their demographics.

#### 3.Structure of the TINP:

**Processes** (revised by Kristen from a combination of older documents)

#### Protocol to enter a new child into TINP:

To be added to the TINP, child must be found on a (1) medical mission, by (2) the group of Midwives in the pilot project, or (3) presented to a health promoter.

Requirements:

- Must have a cleft and/or palate
- Under 1 year old
- Underweight and/or malnourished (confirmed by Doctor on Triage, or Health Center)
- Unable to breastfeed
- Family lacks resources to purchase milk necessary for growth of child
  (A small economic assessment of family will determine acceptance into program. This consists of the promoter visiting the home and taking pictures to get an idea of the family's need)

If child is found in Triage mission they can be added into the project at the mission, with the authorization of the PfS Medical Director (the bottom of the triage form will be filled out and approved see ANNEX 15)

If a child is found by a promoter, they must go to a Health Center to be checked by a doctor to confirm the cleft and low weight/malnutrition. The promoter then must fax the bottom of the triage sheet into the office to be approved by the ACPC medical director and added to the system.

If a child is identified by the Midwives they will call Julio (or promoter who is in charge of family visits in the area) and he will visit the family to do an assessment (fill out the bottom of the triage sheet) and fax it to the office to be approved by the ACPC medical director and added to the system.

Information needed for each child:

- Full name of child
- date of birth
- weight at birth
- start date project
- initial weight
- name of parents
- address
- picture
- promoter who is in charge of this child

Once child is approved by the Medical director, the ACPC secretary or project coordinator, will enter the child's information: date of birth, weight at birth, start date in project, initial weight, and photo into the data base and also the monthly growth spread sheet. Once the child has been entered, the promoter in charge of the region (Myra, Aurelio etc) will be informed to visit the home and explain the project to the family; the activities and the responsibility of the parents will be included. If parents agree to the conditions of the project they will receive their first month supply of milk and a special squeezable bottle for cleft babies (see below).







Responsibilities for each party involved in the TINP:

#### Responsibilities for parents of children in project:

- 1) Attend Education session 1 x per month
  - Transportation will be reimbursed for 1 parent roundtrip- these sessions may be changed to once every 2 or 3 months alternating between the home visits so there is at least one contact each month
  - Parent and child must attend monthly training sessions.
  - Need to bring updated health center card "carnet".
  - Receive milk if all project requirements are fulfilled.
- 1) Visit local health clinic 1 x per month
  - Same day or at least same week each month!
  - Child must be weighed and all vaccines up to date (*Medical Director would like ACPC promoters to weigh child and get the HEIGHT of the child, but still visit the health center each month*)
  - Health "carnet" needs to updated
- 2) Must be available for 1 x per month home visit
  - Must demonstrate how to prepare milk and give it to the child
  - Promoter will weight and measure height of child and check the hygiene of the house
  - Pictures taken
- 3) Only give milk to the child in the program. Cannot sell or give to other members of the family.
- 4) If child does not gain weight one month, they must take the child to see a doctor to identify the problem. If a child continues to not gain weight or visit the Doctor, the ACPC Medical Director must be informed and has the final decision to remove the child from the project for not complying with the requirements.

#### Requirements of the Coordinators:

#### Monthly education session

- 1) Give dynamic health workshop
  - topics can be found in the book that was given to each promoter
  - Themes include: hygiene, nutrition, diarrhea, safe water etc. Each session should be different and planned ahead of time.

- Repeated in each session: how to prepare formula, how to use the bottle, the importance of lip and palate reconstructive surgeries, requirements for the project, and time for questions
- 2) Check Health Center "carnets" and record data
  - Date of health center visit
  - Weight of child
  - HEIGHT (new)\*
  - Growing or not growing
  - Observations or issues
  - Take photograph of child
- 3) Distribute milk
  - 4 cans of Nan1 for children under 6 months
  - 4 cans of Nan 2 for children between 6 months and 1 year old
  - 1 bag of NIDO for children over 1 year old
  - Record milk given
  - Signature of parent (thumb print if they cannot read/write)
- \*Substitution of Incaparina for a portion of the formula, more detailed explanation mentioned later in this report

#### Monthly house visit – may be done by helper of coordinator

- Coordinate to ensure mother and child will be present
- Verify milk is being used properly
- Take picture of child and home
- Give small health talk, focus on improving hygiene
- Get signature of parents as proof of visit

#### **End of month report** (specific template)

- All data obtained from education session and home visits
- Date of health center visit, weight, progress, photograph, observations
- List of attendees, signatures, milk distribution
- All pictures taken
- Dates and distance traveled for reimbursement

#### Attend training sessions given by PfS

- Trainings for Collaborators and Area Representatives
- How to give effective health talks important to do twice a year
- Understanding importance of program
- Training on preparing milk
- Nutrition training
- Hygiene training
- Computer & Camera training

#### Requirements for ACPC/PfS Staff:

- Collect and organize the reports from each month
- Train the coordinators twice a year on the previously mentioned skills and information
- Reimburse coordinators for their travel and work

<sup>\*</sup>PfS is in the process of deciding what would be the best time/place for the promoters to weigh and measure the height of the children each month. If we switch between monthly group training sessions and home visits depending on the month-making sure there is at least one contact made each month, the promoter would do this at that time.

- Deliver Milk to coordinators. (For Alta Vera Paz region, there will be a storage center in Coban, the capital city of the department in order to make one big shipment instead of many small deliveries)
- Be available to support coordinators as necessary
- Evaluate a sample of participants each year in order to access satisfaction, knowledge, and ability to complete the projects competencies

#### **Project Policies:**

- A child in the nutrition project will be supported as long as they fulfill all requirements of project and after they have had both cleft and palate operated.
- Parent of children in Nutrition Project must attend all monthly education sessions.
- Child must have an updated health center "carnet". With a weight for the month and all vaccinations.
- After the child has been operated they will be supported for one additional month or until they turn 1 year old.
- If a child is not gaining weight the family needs to take the child to the local health center for consult. This needs to be verified by the collaborator. Also need to assess whether or not milk is being used properly or if not, need to determine if child should continue in program. The medical director of ACPC makes the final decision as to whether or not a child should be taken out of the program for compliance issues.

#### 4.Budget:

Major costs of the TINP are spent in formula and reimbursement for coordinator's services.

The TINP supplies families with Nestlé's milk formula Nan1, Nan2, and NIDO.

- Nan 1 is for children from birth up until 6 months of age as the sole alimentation
- Nan 2 is for children 6 months old until 1 year old can be given along with gradual implementation of other foods
- NIDO is for children a year and older to be used as a supplement to other food

Depending on their age, each child receives one of the following:

- 4 cans of Nan 1
- 4 cans of Nan 2
- 1 bag of NIDO

Nestle sells all formulas to PfS at whole sale price:

	Q89.28		
NAN 1 Formula Infantil 12x900g	(\$11.60)	x 4 cans	Q357.12 (\$46.4)
	Q84.78		
NAN 2 BL Formula Infantil 12x900g	(\$11)	x 4 cans	Q339.12 (\$44)
	Q169.50		
NIDO + 6x2.2kg XP	(\$22)	x 1 bag	Q169.50 (\$22)

(\$1.00 is equivalent to around 7.7 Quetzales (Q))

#### Other Costs:

• Transportation of one parent to monthly meeting: depends on distance traveled, averages Q20 (\$2.60)

• Coordinators of the program are paid for a day's work to prepare the monthly workshop, to visit the families, along with mileage reimbursement for travel.

The most recent estimate for average cost per child per month: is \$38 (this was a special whole sale discount arranged through the Central American representative of Nestle)

It requires an average additional \$36 to deliver the formula, provide education, and monitor the growth of infants.

This in total was \$74 per month per infant

#### 5. Current Demographics of TINP:

The TINP is currently working with children in the departments of Alta and Baja Verapaz and Quiche

Current Coordinators in the TINP by region:

Alta Verapaz: Mayra Chen (Julio Chen Works as the helper to do home visits)

Quiche: Aurelio Cordova



Map of Guatemala divided into the 22 departments or states

Number of children who have graduated through the program (undergone both cleft lip and palate surgeries): 10

Number of children currently in the TINP: 43 total

29 de Alta Vera Paz

13 de Quiche

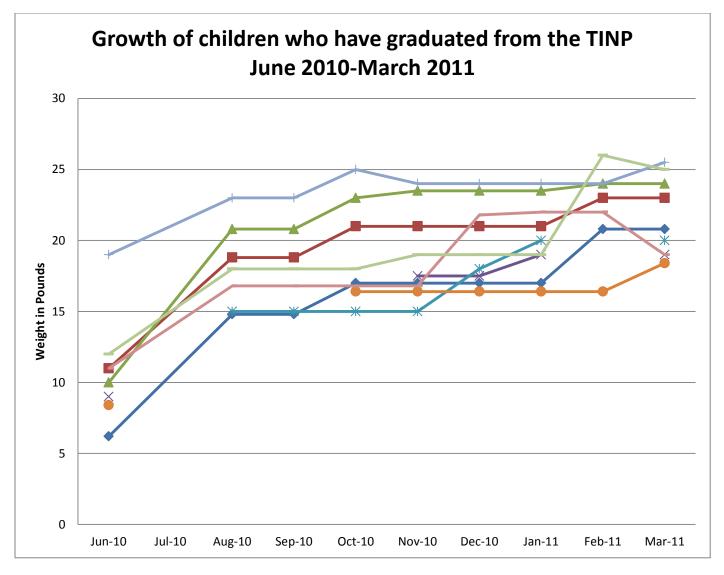
1 de San Juan

Average Age: The children range from 2 months to 26 months and the average age is 1 year old

Average time in project is one year

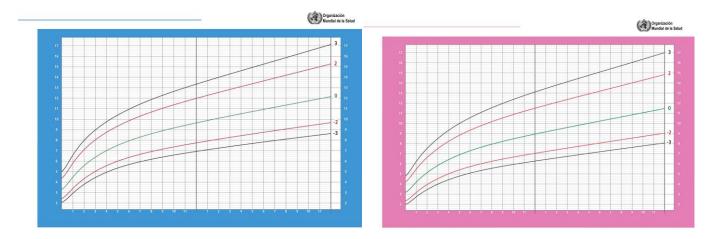
The typical infant is in the PfS Nutrition Project for one year due to the following factors:

- Infant enters the project in a severely malnourished condition and needs time to gain enough weight for surgery
- The infants require two surgeries separated by at least 6 months
- Infants ready for surgery often must wait for the next available surgical team



This graph shows the monthly weight gain of 9 of the 10 children that have graduated through the TINP after going through successful lip and palate surgeries. There is a large weight gain the in the initial months of enrolment for all

children and from then on steady weight gain and occasionally weight maintenance. This graph suggests a positive relationship between project enrollment and weight gain.



These children growth charts were produced by the World Health Organization (blue for boys and pink for girls). It is the goal of the TINP to help achieve a weight within the normal range in line with these graphs. This is the guide PfS uses to make sure each child in the TINP is at a healthy weight. The previous graph, displaying the weight gain of previous TINP participants, displays a significant initial weight gain upon entering the project and then continuse on in the normal weight range for their ages.

#### 6. Satisfaction of parents

Satisfaction of parents in project based off of 10 interviews: Copy of interview questionnaire along with complete results can be found in the ANNEX 3 and 7.

- Parents are very content with the help they are receiving and have seen drastic changes in the health and weight of their child
- Myra, Julio, and Aurelio (the coordinators and helper of the TINP) are doing a fantastic job! The families have learned a lot from them and appreciate their support.
- All but one of the families were able to explain or demonstrate how to prepare the formula and clean the bottles.
- The monthly educational sessions and milk delivery have created a support system with the families who have children with clefts. Before the program, all but one family had never known anyone with a cleft and felt alone and guilty.
- Testimonials from families who have graduated through the TINP would be very helpful to give families an idea
  of what to expect. Also this would help disclaim rumors that sometimes scare families about the surgical
  process.
- Most families reported that the formula they receive does not last the whole month, especially for children
  older than 6 months. It will be important to stress complimenting the milk other nutrients and possibly looking
  into providing "incaparina" a supplement that is more economical and full of nutrients for children older than 6
  months.
- Through observations (4 house visits) along with comments during interviews, home hygiene has improved as a result of the project and children do not get as sick as often as they used to.

#### 7. The Milk Formulas:

Incaparina was created in 1959 by the Institution of Nutrition of Central America and Panama (INCAP). This supplement was developed in order to combat the incidence of severely malnourished infants in Guatemala. It is a very well-known product in Guatemala. It is a powder with many added nutrients, vitamins and minerals. It can be prepared by simply boiling water and mixing in the formula. It is usually consumed as a warm drink. This drink is often prepared for children at schools and routinely prepared in the home. It is readily available in all parts of the country and priced very economically. Currently in local stores a small 450g bag is being sold for Q10 (~1.30). Below are the nutrition facts



When comparing Incaparina to NIDO, which is the milk formula that TINP is currently giving to participants over 1 year old, Incaparina for the same amount of calories (serving size: 73kcal) contains almost double the amount of protein that

NIDO does (4 grams compared to 2.4 grams). Incaparina has more Potassium and is comparable in the other minerals and vitamins to NIDO. NIDO because it is a milk formula, contains more calcium.

In order to provide the child with the same amount of calories 5 of the 450 gram bags of Incaparina would need to be purchased. Each one of these bags cost Q10 ( $^{\circ}$ \$1.30) at the local stores. Therefore a month supply of 5 bags would cost Q50 ( $^{\circ}$ \$6.50).

Currently PfS is buying a 2200 gram bag of NIDO each month that cost Q169.50 ( $^{\sim}$ \$22) this is over three times what the monthly cost for Incaparina would be.

#### 8. Looking for governmental support in *Partner for Surgery*'s efforts:

#### Interviews with the Guatemalan Ministry of Health in the Department of Alta Verapaz:

#### **Department of Statistics**

Interview with Lcda. Fabiana Calsis, Coordinator of Statistics for the past 12 years in Alta Verapaz (July 27, 2011)

Fabiana explained that the Health Department mainly works administratively, however she provided a list of services that the health system provides in Alta Vera Paz along with a list employees through the MSP that are contracted in Alta Vera Paz (see ANNEX 14).

The information that Fabiana presented was detailed. It was collected in 2010 and reported on the top causes of morbidities and mortalities. She explained that every health center, health post, and hospital had to send in weekly reports recording how many patients were seen and what they were suffering from. She said that one of the biggest problems is that the doctor's handwriting is very hard to read. Sometimes the doctors themselves are not the ones filling out the forms. These could be some of the problems with the statistics. Also, the statistics that they receive are only the cases that seek care from the health centers. This does not include cases who do not report to the MSP centers. The system seems to be improving.

The MSP statistic department has more detail then PfS expected going into the interview. As far as emphasis on cleft lip and palate, there were only 31 children reported as having this problem in the department Alta Verapaz in 2010. In the TINP alone there are more children with these deformities. This is an area that could be improved.

General comments about the MSP annual report:

- Population in Alta Vera Paz: 1,078,951
- Total births in 2009: 26,503
- Total births in 2010: 27,513, 55% of these births were attended by a midwife.
- The report breaks down the number of people living in rural and urban regions. The rural population is 4 times greater than the urban population. There are 2,057 communities in the department Alta Vera Paz and 2, 156 midwives.

These statistics are underreported and missing out on a large number of conditions in the communities, especially the remote communities. However, they have a system to collect statistics, which is important. They are going to start coding their statistics with patient's name in order to avoid counting the same person twice.

Fabiana explained that although there is a code for clefts and other birth defects on the clinic patient forms, many of these cases may not make it to the health centers, or the staff in the centers has not been specifically trained on identifying these deformities as a priority. This could be an area of improvement that we could help emphasize.

See the attached report (ANNEX 14) There is not an emphasis on birth defects. But it shows prenatal visits and the top diseases and causes of death. The important information from this interview is that there is a system in place to report all cases that come to the MSP health posts throughout the whole department.

#### **Department of Nursing**

Interview with Lcda. Maria Antonieta Lopez, Reproductive Health Coordinator, she has 6 years of experience in the department of nursing (July 27, 2011)

She explained the structure of the MSP in Alta Vera Paz. There are 19 health centers of these centers, 14 are permanent attention.

#### **Network of Services:**

- 14 Permanent Attention Centers (24 hour attention)
  - o Focus on Maternal and Infant Health, each one has at least 3 doctors on staff
- 1 CAMI Centro Attention Maternal Infant, Has surgical resolution and is located in San Cristobal.
- 2 District Hospitals (located in Frey and La Tinta)
- 1 Regional Hospital in Cobán
- 1 CENAPA Centro de Atención Paciente Ambulatorio
- 1 Puesto Sauld Fortalecido (Raocruha)
- 50 health posts, many times no Doctor, they have a nurses aid or nurse that Works 8am-4pm during the week.

When the high rate of children with clefts in the department was mentioned, she thought the cases were isolated and uncommon. This is most likely due to underreporting.

Lopez explained the program with the midwives. There are two divisions the *area de influencia* which is concentrated in the urban areas of the department. This group of midwives has been working since the Ministry of health has been working. However in 1998 they created the *Extencion de Cobertura* which is organized by an NGO to train and monitor midwives in the rural areas of the department. The job of each midwife according to Lopez, is the following:

- Accompany the pregnant women in the community to at least 4 pre natal controls
- Attend the birth in the home or take the woman to the health center to give birth
- Visit the woman and child for 40 days after the birth to make sure the child is growing healthily
- Report births to the ministry
- Meet monthly to receive training and report the events of the month

Nurses are supposed to train the midwives; however thus far there has not been specific training on how to deal with babies with clefts or infant nutrition.

Jesus Vasquez is the coordinator of *Extencion de Corbertura*. After explaining PfS's pilot program in Chicixil with the midwives, Lopez acted very interested in planning a training and working in this area.

According to Lopez, prenatal control has increased in the past couple years in Alta Vera Paz. She believes that this has something to do with the *mi progreso* which is a government program that provides Q150 per month for each child that a woman has during pregnancy and until the child is 2 years old. This money is only given when the mother goes to get 'prenatal controls. From conversations with people, this program does not reach all of the mothers in the country. However according to Lopez it has increased number of prenatal visits.

The norms for prenatal services through the MSP are:

- First control, includes all lab tests
- Vitamin supplements including folic acid
- Assistance at birth

All of these services are free for mothers. Sometimes the lab tests are hard in the rural areas but easier in the urban areas. The vitamins are always on hand, for those mothers who come to the controls. There are 11 laboratories in the department.

When a baby is born with cleft lip or palate they can only refer them to a medical mission or the capital where an operation would cost a lot of money.

The Health Department administers vaccine campaigns and health education along with the distribution of brochures and flyers. These services are usually accomplished with the help of the health educators in the communities.

The nurse concluded by agreeing that it would be very interesting to collaborate in health education for the midwives. There are three thousand midwives and two thousand are in the *extencion de cobertura*. She recommended PfS talk with the department of nutrition to learn more about programs focusing on infant nutrition.

Nursing seemed very open to collaborating and help make cleft lip and palate reporting a priority in the communities. Overall the interview was very positive.

All three departments in the Health Department were very supportive of PfS's TINP and the midwives pilot project.

The MSP has teams that visit communities monthly. Each team is made up of:

- Nurse
- 2 health educators
- 1 facilitator professional
- FC (Facilitators in the Community) in each community, these are the people that run the most basic health posts
- And each community usually has at least 3 midwives.

This team covers 20 communities and they visit each community once a month. In these visits they give vaccines, weigh the children under 5 years, distribute the nutritional supplements (microvital), and deal with general health concerns in the community. In the department of Quiche for example, they have three areas that come together monthly and give reports of what they found in their community visits. This is another way that the MSP is facilitating sharing information. In theory, these groups are seeing every community in the department each month. Working with the FC or possibly attending these monthly "area meetings" to give them a sheet to report clefts or any other birth defect could be a informal way to generate the statistics that PfS needs. The FC seems to be the contact person that knows about birth defects more than the MSP health centers, according to some of the parents in the TINP.

#### **Department of Nutrition**

Interview with Lcda. Silvia Perdomo Molina, Coordinator of the MSP Nutrition Program (July 28, 2011)

MSP nutrition program, which was started in 1995, has 3 primary functions:

#### 1. Supplementation of Micronutrients

- a. This begins at 6 months of age. Every child after 6 months until 2 years receives Vitamin A and "Macrovital", which is a little packet of minerals and vitamins that is supposed to be ingested by the child every day.
- b. 60 packets are given to children every 6 months, however they only last 2 months. Unfortunately that means the majority of the year the children are not receiving this supplement.
- c. These are distributed in every health center, post, and station (saneamiento) in the 17 municipalities of Alta Vera Paz.
- d. These supplements are donated from international organizations, the MSP doesn't have control over them, and often times doesn't know when they will arrive. Normally two large shipments come a year.
- e. After 5 years of age they give all children **Iron supplements**. They give women **Folic Acid** supplements to be taken once a day for women 10 years on to 49 years of age.
- f. These supplements are all FREE. The issue is there is not enough for everyone and many people do not have the knowledge of the importance of these supplements. Many do not take them due to lack in health education.

#### 2. Growth Monitoring

- a. Weighing and measuring the height of the children each month.
- b. Each child is given a *cardnet* or information tracking card at birth that records the vaccines they have received and their weight and height each month. The cards were very nice looking and complete. They have new versions for this year.
  - i. For children under 2 years old, the checks are monthly. For children 2 until 5 years old they are checked every 6 months.

#### 3. Vigilance

- a. Treatment when a child comes in with severe malnutrition.
  - i. At times of disasters
  - **ii.** When they are identified as having acute malnutrition. Based on weight and height for their age.
  - iii. Treatment:
    - 1. When the children are identified but a health entity in the area, they are taken to the closest hospital and put in a Nutritional Recuperation Center. There are 4 in Alta Vera Paz:
      - a. La Tinta
        - i. This center has support from PLAN International
        - ii. It is a part of the hospital but separated, it is a very nice facility
      - **b.** Frey
        - A small room in the hospital, easy for the children to contract other diseases while there, due to the contamination from the rest of the hospital
      - c. San Cristobol

**i.** Same problem, in that it is part of the hospital, and many children are susceptible to get sick while there.

#### d. Tamau

i. This one is not directly part of the MSP. It was recently started by the Catholic Church. The MSP collaborates in the efforts there. It is a small space that could use more support.

#### 2. Treatment that children receive:

- **a.** 2 Formulas that are administered, depending on severity and age for children over 6 months old.
  - i. F75 and F100, each bag of formula makes 2 liters and is enough for one day of feeding.
  - ii. On average the child will stay in the center for 2 months.
  - iii. This service is free when the formula is available.

#### b. For children under 6 months

- i. Bebelac, this is the formula that the MSP purchases
- ii. **Nan 1** this one is expensive and harder to get, In Tamau the nuns are able to buy this type of formula, but MSP cannot

#### c. Ambulatory Treatment

 For children older than 6 months, they administer an A.T.L.C. "plumpy nut" which can be given to children to consume in their homes instead of having to be admitted to a center.

#### d. Results of this program

- i. Not that great. Many times the child will be back in for more treatment because they were unable to keep on the weight at home.
- **ii.** Lack of health education component. The centers do not have health educators that are able to teach the mothers the importance of taking care of their child and preventing malnutrition.
- **iii.** At this moment there is no formula to give the children. They are waiting for more donations.
- **iv.** The conditions are not very accommodating in these centers. There are no places for parents to stay, bathe, or eat. This makes it very hard for families to come.

#### **Goals and Aspirations for the Future:**

- Build a Center for Nutritional Recuperation in Coban. They feel that this would be more accessible to more people in the department. Especially for the families who live in very rural areas almost everyone knows how to get to Coban or can find a bus that goes there.
- Start programs for ReLactancia

Silvia introduced a type of Breast Pump they are trying to promote. It is made of a syringe that is cut open and used to suction out milk. She explained that it costs Q2.5 which would be something reasonable for most mothers to buy. She also mentioned that they sell breast pumps for Q20 in the pharmacies. After checking in the pharmacies in Coban this was confirmed. The pharmacy had a glass breast pump for Q25 they also have them in plastic, but mothers say that the glass one is more comfortable. This price seems more sustainable than the \$15 breast pumps PfS has from the states. Also after looking at the ones PfS has, they have many parts and could be confusing to the mothers. They run the risk of losing a part and not functioning. The breast pumps found at the

pharmacies had two parts and looked pretty simple. This would be good to talk about with the lactation expert to decide which pumps are most cost effective.

- They also want to solicit funds to try and buy/receive special bottles for clefts. Right now the MSP does not have
  any programs that deliver milk supplements or bottles to babies with clefts and or other deficiencies to
  breastfeed.
- Silvia explained that to date the MSP nutrition program has not worked with the midwives. This would be a good group to work with since they are witnessing the births and first 40 days of the child's life. Silvia seemed very interested in making this connection.
- Create more programs for community health education and also education in the centers of nutritional recuperation. Lack of health information/education is the number one problem in Silvia's eyes in regards to malnutrition.

#### **STAFF:**

In the area de Nutrition there are 3 full time staff that work in the *Area de Salud*, Alta Vera Paz. In each municipality there is not a representative. There are health educators in many of the health posts in the department, but many do not emphasize nutrition. This is an area that they seek to improve. There is a large need for heath education focusing on Nutrition. The system has health educators and also Rural Trainors *Tecnicas Rurales*. The Tecnicas rurales initial job was to be the link between the *extencion de coberatura* and the *area de influencia* which is the urban health centers. Right now both of these groups are working on the growth monitoring of the children in the communities each month.

The health educators work more closely with the schools in the program Healthy Schools *Escuelas Saludables* and Friendly Spaces *Espacios Amigables* that work with the adolescents. They are not going door to door and often not making it out to the most isolated and remote communities.

#### **Overall comments:**

Silvia was very educated and passionate about her work in nutrition. It was obvious that funding and lack of staff are the major issues affecting the nutrition project. The three components of the nutrition project are well planned out, but not executed in the intended way due to financial and personnel limitations.

Silvia was very open to collaborating to generate statistics and also to train health promoters/midwives in nutrition topics.

The concept of Relactation was something we have not considered. According to Silvia and published studies, a woman can produce milk if the baby provides suction. It doesn't matter if she has never been pregnant or if she stopped producing milk for a period of time. This is something that could be very useful with mothers. She also proposed a more economical form of a breast pump and a way to simulate suction in order to attempt relactation.

Connecting the TINP with the MSP could only improve its results. The MSP has many connections that could potentially help with funding and also methods that are cheaper and may very well achieve the same results. However the biggest strength of the MSP is that they have a system of communication from the top down to (in theory) the most remote communities in the department. Working with them would be a great way to expand PfS's coverage. Silvia was told she would be involved in communication and further plans with PfS, she was very excited.

#### 9. Other organizations working in the same field:

#### Partners in the Field mentioned by the MSP:

- Cooperación Sueca (Asdi)
- Mercy Corps
- Plan International (works in Carcha, La Tinta, and parts of Tucoro)
- Tula Salud
- Adri (Tucoru)
- Fundación Contra el Hambre
- Medical Teams
- Fundación Guierrmo Toriello Lopez
- Foundation Contra el Hambre
- Foundation Damion
- A.T.L.C. they are supplements for children under 5, like chispas or little packets of micronutrients
- Sesan

Through conversations and internet searches a preliminary spread sheet was put together of organizations that could be potential partners for PfS (see ANNEX 11). These organizations can become important players in the sustainability of the TINP for their connection with the government, communities, and/or similar missions.

#### 10. Midwives Pilot Project

Although the Ministry of Health is concerned with monitoring their department's health issues and services used, the system lacks the capacity to generate reliable statistics at the present time. Therefore *Partner for Surgery* decided to start a pilot project to get statistics from the people who witness all the new births in the region, the midwives. The pilot program is working with 26 midwives in the regions of Chicixil a region in the department of Alta Verapaz.

As the ministry explained, the midwives are organized by the Guatemalan Ministry of Health.

Partner for Surgery has established a relationship with this particular group of midwives and hopes to expand this effort to other groups if it proves successful. Although PfS staff had visited this group before my arrival in Guatemala it was still in the early phases. One of my tasks was to develop a form for the midwives to fill out each time a baby was born. The form had to contain as little words as possible given that the majority of the midwives do not read or write and even less understand Spanish. The half sheet form has pictures of different birth defects (cleft lip, cleft palate, clubbed feet, Syndactyly-webbed fingers or toes, Polydactyly- extra fingers or toes). See ANNEX 10

Mayra Chen, the TINP coordinator, and I attended the midwives' monthly meeting on August 25, 2011. The Agenda of our presentation can be found in the ANNEX 6. To summarize, we engaged the group of 20 midwives in icebreakers, an educational talk on nutrition after the first 6 months of life, a background on the TINP, how to identify clefts, and introduced the forms to the midwives with an explanation on their use and received their approval and compliance to participate.

#### Midwives meeting August 25, 2011:

A 2 hour workshop was given by Mayra Chen (ACPC promoter) and Kristen Mallory (PfS intern). It started with a icebreaker followed by orientation on how to feed children after 6 months of age. First we asked the women what types of foods were found in the communities in which they worked. They named more protein (eggs, cheese, beans, and meat) then I had imagined were available to families. From the list that the midwives gave us, the availably of the foods

may not be the problem, maybe education is what is needed. Numerous people have told us that many families sell fruits and vegetables to buy unhealthy foods in the local stores. To learn that nutritious food was already available in the community was promising information.

Through the nutrition talk we discovered that there was a spectrum of information among the midwives. The majority of the midwives are aware of the importance of breast milk. However several did not know that coca cola and coffee were unhealthy for babies. Nutrition knowledge seemed to be something that could be improved. In regards to preparing foods for children after 6months of age, they said that the members of their communities had ways to mush food and puree it. Whether it be a hand grinder, blender, or utensils, there seemed to be something all homes could use to prepare food. Only one out of the 20 midwives had heard of or seen a breast pump. They were interested to receive training on this topic.

The midwives were very active and participatory throughout the discussion. It was a good group to work with.

There were 22 births the month before the meeting. None of which were born with clefts. They attempted to fill out the forms from the month before, but are more comfortable with the new ones (less reading involved).

The details on how to fill out the forms were explained. A system of monthly collection was determined. The MSP nurse coordinator Matilde Cantoral agreed to collect the forms and bring them to the health department each month. More forms will be needed because only 100 were delivered at the meeting.

20 out of the 26 midwives in the area showed up to this meeting. Five of them live far away and do not attend the meetings. There was a Community Facilitator meeting going on right next to the midwives meeting. There is a connection between the two groups.

Matilde, who is organizing the group of midwives through *Extencion de Cobertura* is willing to collaborate. She said there is usually good attendance at the monthly trainings



Breast pumps that have been donated to PfS for this project/Midwives with the newly developed check off sheets

#### Other Conversations:

#### **Midwives**

Interview with: Augustine Choc and Teresa Chu midwives from La Nueva Esperanza, Alta Vera Paz

They explained that midwives have been a strong presence in the Guatemalan communities since the beginning, but 7 years ago they began to collaborate with the Guatemalan Ministry of Health. The ministry of health does not pay the midwives, but provides training sessions. The midwives are required to work 2 shifts in the Health Center each month. Earlier an organization called: "Medico del Mundo" trained the midwives, now the Doctors in the Health Centers are responsible for training sessions once every 2 months. The material provided is: danger signs before and during child birth, and what to do when someone is sick during pregnancy. They knew a lot about placenta and the different checks that one should do during birth. They are required to give a report to the Health Center on the births that they attended.

They talked a little about the nutrition of the communities in which they work. They explained that tortilla, egg, beans, meat, wiskil (a green potato type vegetable) can be found in the community. They often sell fruit (oranges and banana) and vegetables instead of consuming them in the home.

They talked about types of treatments/food that they recommend to mothers who have trouble producing breast milk. They had never seen a breast pump. They feel under supported as far as equipment to attend births is concerned. Also not receiving any compensation for their work is a struggle and may affect the motivation of midwives.

• Interview with Cleotilde Pereira midwife from Chiquixji

She was one of the only women in the group who could speak Spanish; she stayed after the meeting with us to talk about her work as a midwife. She has been working as a midwife for 4 years now.

- The activities they do monthly are the following:
  - Attend one training each month
  - o Give one health talk to the pregnant women in the community
  - Attend to the births of the community
  - 5-6 visits postpartum, to help the mother lactate and check on babies health and growth

They are trained through the consults with Matilde (the MSP nurse coordinator of the area) *Extension de Cobretura* comes to Chiquixji once a month and reimburses the participants for their transportation. The themes that are covered are the following: pregnancy, vaccines for babies and pregnant women, information for during the birth and also for after the birth.

It is the decision of each family to pay the midwives. Many families do not have enough to pay the midwife. The *Extention de Cobertura* does not have money to pay them for their work. They give each midwife Q50 for attending the monthly meetings.

Cleodilde normally attends between 2 and 3 births a month, most of which are in the home

She reports the births that she attends each month to the Facilitator of the Community (FC) and the Nurse in charge of the area.

In the event that a child is born with a cleft the midwives inform the FC to look for help

The number of midwives in each community depends on the size of the community. The larger communities have 2 or 3 midwives, however the smaller ones only have one. She also explained to us that each month a team (1 nurse,

facilitators and health educators) collaborates with the FC and midwives to give vaccines and check on anyone who may be sick. During this time, information is shared and then passed on to the Ministry of Health.

In each community there is one FC who is in charge of keeping track of the weight of children and vaccine records. When the medical team comes for the monthly consult they need to have the underweight children and those in need of vaccines. There are also 5 vigilantes who assist the FC.

#### 1 community facilitator

• Interview with Don Pedro Para Kaku, one of the FCs from Aldeza Tana who assisted the monthlytraining in Chicixil. He has been working as a Community Facilitator for three years now. This group of health workers is also organized by ABK-DEC (NGO-Extencion de Cobertura). Like the midwives, these community workers are not paid, but rather given incentives to participate in activities. Their transportation costs are covered along with food while working.

He reported that there is a big disconnect of information between the midwives and the FCs. Technically the FCs are supposed to report all births and child statistics to the Ministry of health (Extencion de Cobertura). However, Pedro told me that he often does not hear about the births from the midwives in the community. This seemed strange because the FC along with other community vigilantes all live in the same community. This could explain some of the lost data.

# IX. Conclusions & Recommendations:





#### Overall:

The revised program goals, structure, and protocols will make the project's processes consistent and standardized. The budget still needs to be analyzed with more detail. The implementation of Incaparina as an alternative to formula and staggered monthly workshops are a couple of ideas to save costs in order to add on more children. Implementing breast pumps would also lower costs. Currently the TINP is spending too much money per infant per month to sustain the project for the long term. Strategies to lower costs and/or make the project more effective should be a priority.

#### Incaparina:

Incaparina, due to its availability, price, and nutritional content, has become a common household food source. After looking at the price compared to the nutrients, Incaparina appears to be a more sustainable alternative to Nan2, and NIDO. These more expensive milk formulas have more calcium than Incaparina, but are comparable in other micronutrients. Incaparina contains more protein and some other minerals and vitamins than the milk formulas.

For children, younger than 6 months, they need to continue receiving Nan1. However, babies who are older than 6 months could consume Incaparina along with Nan2. At 6 months parents should slowly start to introduce foods into their child's diet it would be possible to give half the monthly supply of Nan2 (2 cans instead of 4) and 5 bags of Incaparina which has similar calorie content.

Children who are over a year old and currently receiving NIDO could completely replace NIDO with 5 of the 450g bags of Incaparina. Each bag costs Q10 (~\$1.30) in local stores, 5 bags for a month would cost Q50 (~\$6.50). This amount of Incaparina would provide the same number of calories for less than a third of the price of NIDO formula.

Another advantage to Incaparina is that it is sold in local stores; most people would be able to buy it, less transportation costs if PfS buys it in the communities. This could be a pilot project for a month or so to see how the infants' weights are affected by the switch before deciding to permanently change formulas.

#### Alternate educational sessions and house visits:

In order to cut costs in the TINP it would be practical to limit the group educational workshops to once every 3 months instead of every month. The months in which there is not a workshop the families will receive a home visit where the milk will be delivered along with a mini health talk. In this way PfS will not have to reimburse families for travel costs every month. It is important that there be one contact each month in order to give the milk and monitor each child's progress. During the months in which the group comes together it would not be necessary to also visit each family. In the months that will have a group workshop the project coordinators will have more time to plan the workshop and make it more impactful while continuing the social support system that so many parents mentioned as being helpful. In this workshop the major themes of the TINP should be reiterated along with a new topic to keep families interested. One of these topics could come from the book of *charlas*, or another health *charla* that the promoter finds appropriate.

#### More emphasis on continued Health Education for the promoters:

The triage and surgical missions are great opportunities to increase the health knowledge of patients and their families through educational sessions. The health promoters received a specific "how to give a *charla*" workshop along with a printed resource that spells out specific health talks that can be replicated. However, many of the promoters still lack confidence and practice in giving these talks.

It is important that during surgical and triage missions, PfS staff works with the promoters to plan, organize, and facilitate these health education talks. Continuous feedback and motivation is needed to make this become a habit. At the beginning of each mission, one PfS/ACPC staff member should meet with the promoters who will be working in the

mission for the week. In this meeting groups should be made and, day, time, and health topics chosen. The staff member should make sure that these health talks are executed while acting as a support to the promoters along with helping them solicit participants and providing feedback.

#### MSP system and collaboration

After the interviews with the Nursing, Statistics, and Nutrition departments of the Health Department (*Area de Salud*) in the state (department) of Alta Vera Paz:

- The Ministry of Health (MSP) in Guatemala has a system set up in effort to reach all communities in Guatemala. It is top down. There are Community Facilitators (FCs) and midwives in each community to do the most grassroots and basic health tasks. The communities are broken up into regions that receive a monthly visit from a health team (nurse, 2 health educators, and a professional facilitator). This way, the communities that do not make it to the health centers are still receiving some type of primary care. Statistics are reported to the regions and then on to the Health Department in the capital of each department.
- There is a reporting system in place that's goal is to track births, diseases, and deaths in each department. The Health Department receives monthly reports. These reports however seem to be underreporting clefts and other birth defects.
- The departments that were interviewed in Alta Vera Paz were supportive and interested in the TINP and midwife pilot project.
- The departments of Nursing and Nutrition wanted to be involved in the trainings and implementation of a potential department wide initiative focusing on nutrition and working with the midwives.
- Currently the MSP's nutrition program has not been working with the midwives in the department; however the coordinator is very interested in working with them.
- The MSP's nutrition program would be interested in teaming up with TINP in training midwives on how to make and use breast pumps.
- The limitation of economic resources and lack of health education seem to be the 2 largest barriers for the Health Department's work in Alta Vera Paz.

#### After interviews and workshop with midwives

- The midwives have years of experience and are trained adequately to attend births
- None of the midwives had ever seen or heard of a breast pump. This would be a great training opportunity that PfS could potentially organize with the MSP.
- Because the midwives are not paid they may lack the motivation to report all of the births that they assist.
- The midwives were excited about the project and maybe even more excited that someone cared about the work they do in the communities.
- The team of primary health providers that visit each community monthly would essentially reach all cases of clefts in the region.
- There is still a lack of accuracy in the statistics being generated. Miscommunication among groups could be the cause of this underreporting.
- Midwives in the pilot group understood the birth defect check off forms and were positive and motivated to fill them out. They will need continued support and monthly visits in order to keep motivated.

Plan/Path for the future to ensure stability:

I believe that teaming with the MSP would be mutually beneficial and help secure sustainability of the TINP.

- MSP's commitment:
  - Facilitate the communication system from the communities to the Health Department for reporting birth defects.
  - The MSP's nutrition department could provide breast pump training
  - Begin to help with fundraising for milk/breast pumps
- PfS's commitment:
  - Provide training in how to identify clefts and the importance of finding them early (this could be done by our promoters in each of the areas).
  - Have a PfS promoter attend the monthly meetings to become part of the network.
  - Find surgical missions for the patients that MSP reports to PfS.
  - Potentially work with MSP in the future to do a thorough epidemiological study in the area to find out why the prevalence of specific birth defects is higher in certain regions.

In regard to the milk supplement, PfS should gradually decrease monthly milk purchases for children. If the project becomes a priority for the MSP, eventually the government could help with these costs or help write grants from other national/international organizations.

Eventually, if the reporting becomes more exact and timely it would be possible to switch to solely breast pumps, which would bring monthly costs down drastically and allow for more children to be enrolled. For this reason, the efficiency of breast pumps (which one works best, what method is more likely to produce milk, which ones are cost effective) and the trainings for the midwives, PfS promoters, and whoever else is in the project will be very important.

By connecting with the MSP, this project could turn into a MSP protocol that would have breast pumps on hand and regular trainings. Community facilitators and midwives would be trained to identify babies born with clefts and educated on breast pumps. These babies would be reported to the closest health center to obtain precise records along with receiving a breast pump and proper training on how to use it.

Prevention should also be a focus for work with the MSP. After more studies are done, the goal will be to take action to reduce the risk for clefts and other birth defects. More emphasis will be given to the folic acid supplements along with a complete orientation (health education component) for all women in their fertile years, to understand the importance of taking the supplements. Any other found causes will also be addressed.

#### Strengths of the TINP:

The staff and promoters in the field are doing a great job to support the TINP. Potentially hiring two regional promoters as full time position would be helpful as the project expands.

Parents are extremely satisfied with their experience in the project.

There are more eligible cleft lip and palate patients ready to fill surgical teams quotas.

The TINP has a positive reputation and strong connections with the MSP and a group of midwives in Alta Verapaz

PfS has a very well respected name in the communities in which it serves. The promoters are trusted and relied on by their communities. The people trust in PfS.

The TINP has provided many children with life changing opportunities that would have never had the chance otherwise. (See success stories from the TINP ANNEX:12&13)

## X. Works Cited:

American Society of Plastic Surgeons (ASPS). 2011 Accessed September 2011 at: http://www.plasticsurgery.org/

Celft Lip and Palate Association (CLAPA).2010 Accessed September 2011 at: www.clapa.com

ICAP accessed September 2011. http://www.incaparina.com/incaparina.php

Tighe D, Petrick L, Cobourne MT, Rabe H. Cleft Lip and Palate: Effects on Neonatal Care. NeoReviews. 2011;12;e315-e324

Wyszynski DF, Beaty TH. Review of the role of Potential Teratogens in the Origin of Non-Syndromatic Oral Clefts. *Teratology.* 1996;53:309-317

www.partnerforsurgery.org (and other documents compiled by PfS staff)



## XI. Annex:

