

Expanding Access to Community-Based Rehabilitation for People with Amputation in Guatemala



2022 Year-End Report

Implemented By:

Proyecto de Rangos de Movimientos (ROMP-Guatemala), Zacapa, Guatemala

The Range of Motion Project (ROMP-Global), Denver, United States

Universidad Mariano Gálvez, Guatemala, Guatemala

Unidad Nacional de Oncología Pediátrica, Guatemala, Guatemala

Supported By:

The Pro Victimis Foundation, Geneva, Switzerland

The Dorothea Haus Ross Foundation, New York, United States

The Barr Amputee Assistance Foundation, Chicago, United States

The Posner Center for International Development, Denver, United States

Tawingo Fund, Boston, United States

RTI International, Research Triangle Park, United States

Part 1 - Global Progress



Summary

In 2022, ROMP began the implementation of its 2022-2025 four-year strategic plan. This resulted in major, positive changes in all countries of operation. In Guatemala, we moved our entire clinical operation from our former location in Zacapa to our new location in Guatemala City. In Ecuador, we launched a new location in Quito and began laying the foundation for a satellite location in the Amazon. In the United States, we transformed our warehouse to constantly supply our field locations with high-quality components and materials.

ROMP-Guatemala

In 2022, ROMP produced 27% more care in Guatemala than in 2021 (594.5 PIPs compared to 469.0). Key achievements in Guatemala during 2022 are given below.

ROMP Operational Scorecard 2022																	
SERVICE	ROMP GUATEMALA																
	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Total YTD	Total Goal	To Goal	Status	
Delivery clinic	6	9	8	31	10	5	31	0	0	40	6	13	159	200	41		
Delivery mobile/satellite	0	0	0	0	0	0	1	0	0	0	0	0	1				
CBR graduates	0	0	0	0	0	20	0	0	0	0	0	20	40	40	0		
Socket change	0	1	1	0	0	2	2	0	0	0	2	4	12				
Socket repeat	0	0	0	0	0	0	10	0	0	0	0	0	10				
Microprocessor knee	0	0	0	0	0	0	0	0	0	0	0	0	0				
Running foot	0	0	0	0	0	0	0	0	0	1	0	0	1				
Follow-up, adjustment, change, repair	59	102	114	54	75	93	57	0	27	66	58	36	741	800			
PIPs	35.5	61	66	58	47.5	73.5	73.5	0	13.5	74	37	55	594.5	640	45.5		
CBR Home visits	0	35	38	42	41	36	0	37	35	34	36	19	353	400	47		
CBR Mobilizers trained	16	12	1	0	0	0	0	20	0	0	0	0	49				

- In March, we were awarded a one-time grant from the Posner Center to support the expansion of the CBR Program to children. In April, we were awarded a two-year grant from the Dorothea Haus Ross Foundation (DHRF) to increase our capacity for providing prosthetic care and CBR services to children. In November, we were awarded a three-year grant from the RA5 Foundation which will be applied to CBR.
- In April, we held our first Guatemalan Clinical Volunteer Program of the year, delivering a total of 22 prostheses with a total of 16 volunteers. In July, we held another, delivering a total of 25 prostheses with a total of 18 volunteers.
- In April, we began utilizing OpenMRS, an electronic medical record (EMR) system. The process of developing this system included setting-up a cloud-based server, standardizing and digitizing clinical forms, creating a format for reporting, transferring data from the previous system, and collecting and consolidating feedback to inform the continual improvement of the system.
- In July, we began taking standardized outcome measures (OMs) with all new patients. The OMs are recognized by the International Society of Prosthetics and Orthotics (ISPO), and include the Amputee Mobility Predictor (AMP), Timed-Up-and-Go (TUG), 2 Minute Walk Test (2MWT), and Trinity Amputation and Prosthesis Experience Scales Revised (TAPES-R). They are now taken with patients upon delivery of their prosthesis, as well as six and twelve months following delivery.
- In August, we relocated the ROMP clinic from its former location in Zacapa to a new location in Guatemala City. This move involved renting and outfitting a new facility, hiring and training new staff, acquiring machines and materials, and establishing processes and referral channels. An in-depth report on the rationale and strategy for this move is attached to this report.

- In September, we hired Hyssell Collado, as the Administrative Assistant for the new clinic. Hyssell worked for nearly 20 years at Plan International in Guatemala. She is responsible for administrative aspects of the new clinic, including communications, scheduling, purchasing, accounting, paperwork, and many others.
- In September, we also hired Katherine Villatoro, as the Associate Prosthetist for the new clinic. Katherine has 10 years of experience providing prosthetic care in her native country of El Salvador. Beyond providing care, she manages the clinic warehouse and inventory. She completed her training in prosthetics-orthotics at the Universidad Don Bosco in El Salvador.
- In September, we opened the doors of our new clinic to patients. Since that time, we have had a constant stream of new patients referred to us from the public health system, municipal governments, and via word of mouth. We have also had numerous patients seek care with us who were originally treated in Zacapa during the years prior to the move.
- In October, we hired Mauricio Canales, as the Senior Prosthetist for the new clinic. Mauricio has 27 years of experience providing prosthetic care in his native country of Nicaragua and other countries of Central America. In addition to providing care, he manages the clinic production planning. He also completed his training in prosthetics-orthotics at the Universidad Don Bosco in El Salvador.
- In October, we held the 2022 Mobility Conference at Hospital Roosevelt, the most important public hospital in the country of Guatemala. Dr. Benjamin Potter, the US Army's leading expert on amputation, served as the keynote speaker for the event. This presentation was professionally filmed and posted online by ROMP to serve as a resource for Spanish-speaking physicians throughout Guatemala and Latin America.
- In October, we operated the first-ever Clinical Volunteer Program at the new clinic. A total of 22 volunteers served alongside ROMP staff to deliver a total of 40 prostheses to patients. This program helped ROMP to conduct an important 'stress-test' of the new facility, and determine key areas for future improvement.
- In November, we initiated the construction of a new workshop at the clinic. This building will be the permanent location of all modification and production activities from February 2023 onwards. This project was financed primarily by the Rotaract Norte Club, and the Guatemalan office of PayPal.
- In November, we made an outreach visit to Hospital San Juan de Dios, the second most important public hospital in the country of Guatemala. There we met with the Rehabilitation Department, and discussed ongoing referrals of patients to ROMP and

ongoing educational exchange between ROMP and the Hospital. In December, we made a similar visit to the Hospital of Cuilapa.

- In December, we hosted a visit by Laure Saporta from the Pro Victimis Foundation (PVF). In this visit, Laure had the opportunity to see the new clinic, as well as make a number of patient home visits throughout the Southern and Western parts of the country.
- In December, we hired Davy Martinez, as the Country Director for Guatemala. Davy has significant experience in financial, human resources, and fundraising management in Guatemala. Davy will be responsible for the management of the ROMP branch in Guatemala, ensuring alignment with ROMP's global strategy.

ROMP-Ecuador

In 2022, ROMP produced 103% more care in Ecuador than in 2021 (652.0 PIPs compared to 320.5). Key achievements in Ecuador in 2022 are given below.

ROMP Operational Scorecard 2022																	
SERVICE	ROMP ECUADOR													Total YTD	Total Goal	To Goal	Status
	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec					
Delivery clinic	1	13	19	7	21	10	12	23	15	5	10	17	153	250	48		
Delivery mobile/satellite	0	0	0	0	0	0	0	4	11	0	0	0	15				
CBR graduates	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0		
Socket change	3	1	8	4	3	3	1	2	1	4	0	1	31				
Socket repeat	0	0	0	1	0	0	2	0	0	0	0	0	3				
Microprocessor knee	0	0	0	1	0	1	0	0	0	0	0	0	2				
Running foot	0	0	0	0	0	0	0	0	0	0	0	0	0				
Follow-up, adjustment, change, repair	36	64	100	74	170	76	68	71	65	56	61	25	866	670	-196		
PIPs	22	46	77	50	109	52	49	68.5	70.5	37	40.5	30.5	652	640	-12		

- In January, we opened the doors of our first-ever permanent clinic in Quito. The facility includes several consult rooms, a physical therapy area, a workshop and modifying area, a warehouse, and several offices. We made key infrastructure improvements to the clinical, workshop, and warehouse areas during the first several months of operation. Our clinic now provides an excellent option for patients to receive care, in addition to the ROMP network of allied clinics in Ecuador.
- In March, we held our first Ecuadorian Clinical Volunteer Program of the year, delivering a total of 9 prostheses with a total of 4 volunteers. In May, we held our program, delivering a total of 20 prostheses with a total of 23 volunteers. In August, we held our third program, delivering a total of 12 prostheses with a total of 5 volunteers. In September, we held our fourth program, delivering a total of 14 prostheses with a total of 17 volunteers.
- In May, we held our first-ever Global Leadership Summit in the Quito clinic. This summit brought together the staff and boards of the three ROMP chapters to discuss the future architecture of the ROMP organization. A Declaration of Commitment was co-created and signed by the three chapters. It specifies the chapters' shared commitments on communications, roles and responsibilities, goals and plans, service quality, and boards of directors.
- In June, we began restructuring the ROMP-Ecuador team to improve its effectiveness for this new phase of growth. This involved the elimination of the Ecuador Programs Officer position, and the redistribution of their responsibilities to the new Ecuador Operations Assistant and Ecuador Executive Assistant.
- In June, we were greatly affected by the national strike that took place during the second two weeks of the month. During this time, there was a shelter-in-place order, flight cancellations, road closures, food and water shortages, and instances of

violence in Quito and other parts of the country. This situation forced us to postpone the July volunteer program until August.

- In September, we conducted a mobile clinic visit to the municipality of Macas in Ecuador. The purpose of this visit was to deliver a total of 13 prostheses to patients from this area. We also established contacts to set-up a satellite clinic in early-2023.
- In October, we hired Mireya Moreno, as our new Ecuador Staff Prosthetist. She is originally from El Salvador, but has worked in Ecuador for the past decade in the private sector for prosthetic care. Mireya completed her training in prosthetics-orthotics at the Universidad Don Bosco in El Salvador.
- In November, we signed an agreement to provide prosthetic care to citizens with amputation in the municipality of Lago Agrio in Ecuador. This represented the first time a financing agreement was signed that specifically sanctioned the use of recycled components, like those that fuel ROMP operations. The first group of patients supported through this agreement received their prostheses in December.

ROMP-USA

In 2022, ROMP produced 28% less care in the United States than in 2021 (62.0 PIPs compared to 86.0).¹ In the same period, ROMP brought in 20% more prosthetic components than in 2021 (11,054.0 pounds compared to 9,195.7). Key achievements in the United States in 2022 are given below.

ROMP Operational Scorecard 2022																	
SERVICE	ROMP USA													Total YTD	Total Goal	To Goal	Status
	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec					
Delivery clinic	1	0	1	1	0	1	3	5	2	1	0	3	18	40	20		
Delivery mobile/satellite	0	0	0	0	0	1	0	1	0	0	0	0	2				
CBR graduates	0	0	0	0	0	0	8	0	0	0	0	0	8	13	5		
Socket change	0	0	0	0	0	0	0	0	0	0	0	0	0				
Socket repeat	0	0	0	0	0	0	0	0	0	0	0	0	0				
Microprocessor knee	0	0	0	0	0	0	0	0	0	0	0	0	0				
Running foot	0	0	0	0	0	0	0	0	0	0	0	0	0				
Follow-up, adjustment, change, repair	3	6	3	6	13	4	8	8	4	2	7	0	64				
PIPs	2.5	3	2.5	4	6.5	5	15	11	4	2	3.5	3	62	120	58		
C4C pounds in	630	1109	624	914	569	1041.0	2080	541	312	241	2831	164	11054	10000	-1054		
C4C pounds out	482	635	606	86	551	530.3	222	444	474	336	68	91	4525				
C4C site enrollments	4	2	3	1	4	1	1	1	0	2	0	2	21				
Volunteer Enrollments	26	23	10	30	7	11	0	21	1	2	4	14	149				

- In March, we moved our warehouse into a new facility which is 50% larger than the former one. This allowed for a complete overhaul of our inventory organization and management, as detailed below.
- In March, we hired our first-ever US Program Associate - Maria Pinto - who is now managing the operation of all US programs. Maria is originally from Colombia and has extensive experience in process management and improvement.
- In April, we launched our CBR Pilot Study at the Baylor College of Medicine (BCM) in Houston, Texas. Access-limited people with amputation were identified by prosthetics clinics throughout the Houston area. They went through intake evaluations with physical health, mental health, physical therapy, job coaching, and prosthetic care providers. The providers then convened to develop individualized, interdisciplinary intervention plans for all participants. Research students at BCM then began weekly check-in calls to participants to check the progress of their interventions, and to provide support in scheduling appointments with service providers. The data from the study will be analyzed, written-up, and published in 2023.
- In May, we began the process of redesigning the US Assistance Program (USAP). The first phase was a situation analysis of the current program, which included reviewing survey data, meeting with key stakeholders, conducting SWOT and fishbone analysis, and building an economic model. The second phase was a design process, which included creating flowcharts for the new process, new patient and

¹ Note: ROMP is still confirming some additional appointments that were conducted in 2022 to get a more precise production number for the United States in 2023.

practitioner forms, a new pricing model, and a new user interface. The new program is now in use with all new USAP cases.

- In May, we completed the reorganization of our entire warehouse. This process included moving the warehouse, eliminating all flawed components, organizing components into bins and onto shelves, retraining the warehouse staff on processes, establishing lines of communication between the warehouse and the Guatemala and Ecuador inventory managers, standardizing supply chain control, and standardizing component naming. This effort has led to significantly improved availability and quality of components in Guatemala and Ecuador.
- In June, we conducted a Limb Disassembly Day in partnership with Ability Prosthetics and Orthotics and Penta Prosthetics. This activity involved volunteers disassembling donated prosthetic limbs to recover the prosthetic components for ROMP's use. This event brought in a total of 295 pounds of components.
- In July, we initiated the second-ever cohort of the Wheelchair to Walking (W2W) Program in San Antonio, Texas. In this program, access-limited people with amputation received twice-per-month home visits by care coordinators, as well as physical health, mental health, physical therapy, prosthetic care, and vocational counseling services.
- In December, we began discussions with the Baylor College of Medicine to provide peer-mentoring/clinical education sessions to all ROMP USAP patients. This service will be provided virtually through video calls between Baylor prosthetics-orthotics students and their designated patients. This program will begin in early-2023, and will enable ROMP to deepen the impact of the USAP Program.

Part 2 - Project Progress



Summary

In 2022, the ROMP CBR Program graduated more participants (40 compared to 30 in 2021) and covered more provinces (14 compared to 7 in 2021) than ever before. We created a pediatric CBR protocol, and substantially increased the proportion of children in the program (40% of all participants compared to 7% in 2021). The CBR Program provided continuity of operations during the move from Zacapa to Guatemala City.

Personnel Development

In January and February, we trained a total of 29 volunteer Mobilizers to serve in Cohort 8 of the CBR Program. Most of these volunteers were physical therapy students from the Universidad Mariano Gálvez. Each volunteer was assigned to one participant, and they provided twice-per-month virtual home visits to their respective participant. They documented these visits in a booklet which was returned to ROMP at the end of the cohort.

In August, we trained another 20 physical therapy students from the Universidad Mariano Gálvez to serve as volunteer Mobilizers in Cohort 9. In this cohort, the volunteers provided only virtual physical therapy sessions instead of entire visits. Having tried both approaches, we decided that In 2023 volunteers will conduct entire home visits, under the supervision of ROMP staff mobilizers. We plan to train 40 new volunteer Mobilizers for the two cohorts.

In November, ROMP staff Mobilizer Caty resigned from her position for personal reasons. During November and December, we offset this loss in bandwidth by ROMP staff Mobilizers Zoila and Martha without any issues. In 2023 we will hire a dual Physical Therapist-Mobilizer, who will spend half of their time providing physical therapy at the new ROMP clinic and the other half of their time conducting home visits to designated CBR cases.

Participant Recruitment

In February, we contacted physicians in the public hospitals in the ten targeted provinces of Cohort 8: Chimaltenango, Escuintla, Guatemala, Retalhuleu, Sacatepéquez, Santa Rosa, Sololá, Suchitepéquez, Totonicapán, and Quetzaltenango. We also contacted municipal governments, community leaders, and past participants. Emphasis was placed on recently-amputated patients who did not yet have a prosthesis.

In July, the CBR team recruited from its database of CBR candidates, which had been growing since the initial call for candidates in the beginning of the year. We also made a special call for pediatric patients of the National Pediatric Oncology Hospital (UNOP). This focus on pediatric patients enabled us to greatly increase the proportion of pediatric participants in the CBR Program, which was a major priority this year.

All candidates were administered a short questionnaire to determine if they met the high-level requirements of the program, and then a longer questionnaire to further vet their qualification. Descriptive characteristics of the cohort 8 and 9 participants are given below.

<u>Cohort 8 (February-Junio 2022)</u>				
<u>Sex</u>	<u>Age (Years)</u>	<u>Province</u>	<u>Amputation Level</u>	<u>Amputation Cause</u>
Female = 5 Male = 15	Oldest = 65 Youngest = 8	Alta Verapaz = 0 Chimaltenango = 2	Pie parcial = 0 Transtibial = 5	Diabetes = 1 Trauma = 16

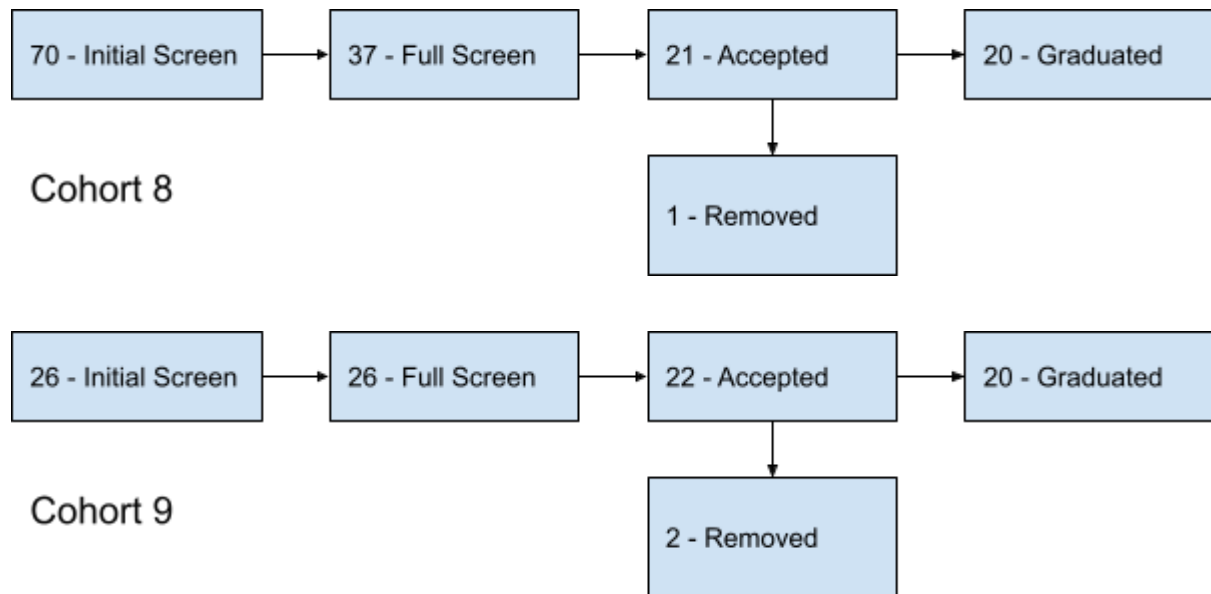
	Average = 37	Escuintla = 3 Guatemala = 9 Jutiapa = 0 Petén = 0 Quetzaltenango = 1 Quiché = 0 Retalhuleu = 2 Sacatepéquez = 0 San Marcos = 0 Santa Rosa = 1 Sololá = 0 Suchitepéquez = 2	Knee disarticulation = 2 Transfemoral = 11 Hip disarticulation = 1 Transradial = 1	Cancer = 2 Congenital = 1
Cohort 9 (July-December 2022)				
<u>Sex</u>	<u>Age (Years)</u>	<u>Province</u>	<u>Amputation Level</u>	<u>Amputation Cause</u>
Female = 10 Male = 10	Oldest = 58 Youngest = 7 Average = 33	Alta Verapaz = 2 Chimaltenango = 1 Escuintla = 4 Guatemala = 4 Jutiapa = 2 Petén = 1 Quetzaltenango = 0 Quiché = 1 Retalhuleu = 2 Sacatepéquez = 1 San Marcos = 1 Santa Rosa = 0 Sololá = 1 Suchitepéquez = 0	Pie parcial = 1 Transtibial = 2 Knee disarticulation = 0 Transfemoral = 8 Hip disarticulation = 8 Transradial = 1	Diabetes = 1 Trauma = 5 Cancer = 14 Congenital = 0

In 2022, we developed a new system for selecting patients as candidates for the CBR Program. In this system, all patients referred to ROMP are administered a standard socioeconomic study in order to determine their relative level of vulnerability. Based on the information they provide, patients are classified as segment 1, 2, or 3. Those patients in segment 1 are the most vulnerable and therefore are automatically considered for participation in the next CBR cohort. If they do not pass that filter, then they are scheduled to receive care in the next clinical volunteer program. In 2023, our recruitment of CBR participants will use this new system, in addition to a special call for up to 30 UNOP patients.

Intake Screening

Candidates who passed the first two screens gave informed consent and were administered a full intake screen, which covered physical health, mental health, physical rehabilitation, and livelihood (or education, in the case of children participants). For those candidates selected as participants, the full intake screen served as their baseline data.

Each candidate underwent a comprehensive mental health evaluation by one of the three psychiatrists affiliated with the program prior to being formally accepted to participate in the Program. The selection process flowcharts of the Cohort 8 and 9 participants follow.



Intervention Planning

Once a candidate was formally accepted to participate in the program, the staff Movilizadores and the participant co-created a list of five goals for their intervention. The Movilizadores then worked with the Field Supervisor to develop a comprehensive intervention plan for each participant.

These plans were digitized and updated regularly by the Field Supervisor. She created a weekly work plan for all personnel based on the plans. The progress of these goals was checked at the midpoint and endpoint visit for each participant.

Home Visits

The staff Mobilizers conducted the first home visit to each candidate prior to formally approving their participation in the program. Following this visit, each participant was sent a pre-prosthetic kit that contained materials for wound care, residual limb bandaging, sound leg care, and pre-prosthetic exercises.

Home visits were conducted twice-per-month during five months in each cohort. During each home visit, the Mobilizer reviewed the participant's progress with the activities specified in the last two weeks of their Rehabilitation Wheel, as well as the participant's activities for the next two weeks. We developed a pediatric version of the pre- and post-prosthetic Rehabilitation Wheels. During 2022, visits were done both in-person and virtually.

In Cohort 8, the volunteer Mobilizers conducted virtual visits with the supervision of their designated ROMP staff Mobilizer. In the event that the volunteer Mobilizer could not conduct a given visit, the ROMP staff Mobilizer conducted the visit. The Field Supervisor continually updated the weekly agenda to track visits.

As described above, in Cohort 9, all home visits were conducted by ROMP staff Mobilizers, and volunteer Mobilizers were instead utilized for providing physical therapy sessions. In 2023, the volunteer Mobilizers will be responsible for conducting the entire home visit with supervision of ROMP staff Mobilizers.

Coordinated Services

The staff Movilizadores coordinated services for each of their designated participants, based on the intervention plans created after intake screening. When possible, these services were conducted via video call to overcome geographic barriers to access.

The volunteer Mobilizers provided physical therapy to participants during both cohorts. In Cohort 8 they provided physical therapy as part of the twice-per-month home visits, and in Cohort 9 they provided physical therapy outside of the home visits that ROMP staff mobilizers conducted. The exercises were specified in the Pre-Prosthetic and Post-Prosthetic Exercises Booklets provided to all participants and volunteer Mobilizers. In 2023, volunteer Mobilizers will continue to provide physical therapy to participants as part of the twice-per-month home visits.

Prosthetic care was provided in-person by ROMP. In Cohort 8 prosthetic care was provided at our Zacapa location, and in Cohort 9 it was provided at our new Guatemala City location. Participants received an initial evaluation during the pre-prosthetic phase of their rehabilitation, and then proceeded to casting and delivery when ready. Participants then received follow-up care as needed. In 2023, prosthetic care will be provided to participants only at the Guatemala City location, which is now the only location of ROMP in Guatemala.

During Cohort 8, group fitness was offered once per month at an outdoor park in Guatemala City. During Cohort 9, group fitness was not offered due to capacity limitations. In each session, the volunteer Mobilizers guided the participants through group exercises that were selected based on the participants' pre-/post-prosthetic progress. In 2023, group fitness will be offered in both cohorts.

Medical care was provided to some participants at municipal government clinics. Physical therapy was also provided to some participants at these clinics. In 2023, we will begin coordinating medical care for participants through the pro-bono clinic of the Universidad Francisco Marroquín School of Medicine.

During Cohort 8, group therapy was done virtually every three weeks by a psychologist affiliated with the Program. During Cohort 9, group therapy was also offered on a couple occasions. All participants were invited to participate via video call. Participants requiring individual follow-up received appointments with one of the three psychiatrists affiliated with the Program. In 2023, group therapy will be offered on a monthly basis in both cohorts.

During both Cohorts, vocational training was provided to participants by ROMP staff Mobilizer Zoila. Adult participants chose from basket-weaving, sausage making, and piñata fabrication. Children participants chose from artesanal jewelry making or basket making. If participants were unable to acquire their own materials, ROMP purchases them. Some participants sold their products, which enabled them to purchase additional materials and grow their small business. In 2023, materials and training will be offered in standardized kits.

Each participant was paired with a graduate of one of the past cohorts of the program who serves as their peer mentor. Each participant was also paired with a community contact who serves as a connection to local resources.

Data Collection and Analysis

Outcome data were taken for participants at the start (baseline), middle (midpoint), and end (endpoint) of the intervention. They were digitized, combined, cleaned, and analyzed for net improvements and declines.

There were a total of 24 adult participants, between Cohorts 8 and 9. In general, most indicators of physical health, mental health, physical mobility, livelihood, and quality of life showed net improvement from baseline to endpoint. The following table exhibits outcomes data for the adult graduates.

<u>Adult Graduates (n = 24)</u>
Net Improvements <i>Satisfaction with health - 3.9% improvement</i> <i>Physical functioning score - 28.3% improvement</i> <i>Role limitations due to physical health - 33.9% improvement</i> <i>Energy/fatigue score - 7.1% improvement</i> <i>Pain score - 0.6% improvement</i> <i>General health score - 11.4% improvement</i> <i>Physical domain - 9.2% improvement</i> <i>Systolic blood pressure - 4.4% improvement</i> <i>Diastolic blood pressure - 9.9% improvement</i> <i>Anxiety severity - 24.3% improvement</i> <i>Role limitations due to emotional problems - 28.1% improvement</i> <i>Emotional wellbeing score - 11.8% improvement</i> <i>Social functioning score - 4.8% improvement</i> <i>Psychological domain - 9.5% improvement</i>

<i>Social relationships domain - 15.7% improvement</i> <i>Prosthesis use hours - 0.0 to 9.6 average</i> <i>Having worked - 26.7% improvement</i> <i>Work all year - 140.0% improvement</i> <i>Work past week - 100.0% improvement</i> <i>Days worked in past week - 117.5% improvement</i> <i>Average income per day past week - 261.6% improvement</i> <i>No expenses covered by family/household - 125.0% improvement</i> <i>Environmental domain - 17.1% improvement</i> <i>Self-reported quality of life - 10.5% improvement</i>
Net Declines <i>Depression severity - 20.8% decline²</i> <i>Blood glucose in-range - 33.3% decline</i>

There were a total of 16 children participants, between Cohorts 8 and 9. Many indicators of general health, mental health, physical mobility, and education showed net improvement from baseline to endpoint. There were some indicators that showed net decline on the same interval.

<u>Children Graduates (n = 16)</u>
Net Improvements <i>Prosthesis use hours - 0.8 to 9.9 average</i> <i>Depression severity - 63.5% improvement</i> <i>Anxiety severity - 59.2% improvement</i>
Net Declines <i>Currently enrolled in school - 9.1% decline</i>

There is a need for caution in interpreting the results in the previous tables. The sample size for both adults and children is small, which means that even one outlier can greatly shift the general trend seen in other participants. Additionally, there is some incomplete data resulting from having collected data virtually and through collection errors. As data is collected for more participants in further cohorts, and as the quality of data collection increases, the real trends in outcomes will come into increasing focus.

In 2023, ROMP will conduct a formal scientific study comparing the effectiveness of the CBR Program to the prosthetic standard of care. This study will be conducted in partnership with Dr. Cody McDonald, an Assistant Professor in the University of Washington Department of Rehabilitation Medicine. In both Cohorts 10 and 11, we will collect the outcome measures for ROMP patients who participate in the CBR Program as well as ROMP patients who simply

² Note: This surprising decline was primarily due to the results of two outliers who pulled the average down.

receive the prosthetic standard of care during that same period of time. This will allow us to evaluate the added benefit of the CBR Program, in an accurate way, for the first time ever.

Other Developments

During 2022, ROMP's work in Guatemala was featured or published in the following outlets:

- An article in *Amplitude Magazine* featuring the ROMP CBR Program:
<https://livingwithamplitude.com/article/multidisciplinary-care-for-amputees-ican-cbr/>
- An episode of *The Fixers* featuring the construction of the ROMP Mobility Park:
<https://www.byutv.org/player/b33285ac-0bdb-49fc-936a-161f51cae50c/the-fixers-romp-guatemala>
- ROMP published a journal article on the 2021 Rapid Assistive Technology Assessment (rATA) study in Guatemala in the *Journal of Disability, CBR and Inclusive Development*: <http://doi.org/10.47985/dcidj.573>
- An article in *Prensa Libre* featuring a patient treated at the Zacapa clinic:
<https://www.prensalibre.com/guatemala/comunitario/imagenes-que-muestran-esperanza-ante-una-nueva-movilidad-y-nuevos-suenos-la-historia-de-oscar-osoy-un-guatemalteco-que-se-encuentra-en-rehabilitacion/>
- A segment in *GuateVision* featuring a patient treated at the Zacapa clinic:
<https://www.youtube.com/watch?v=M4sWhHsl0y4>
- ROMP filmed CBR participant Fatima, showing her during the pre-prosthetic phase of her rehabilitation: <https://vimeo.com/755925896>
- ROMP filmed CBR participant William, showing him during the pre-prosthetic phase of his rehabilitation: <https://vimeo.com/751453836>
- ROMP filmed the 2023 Mobility Conference given by Dr. Benjamin Potter, which focused on the best practices in lower-extremity amputation:
<https://vimeo.com/774052504>
- ROMP filmed the new clinic in Guatemala City: <https://vimeo.com/780798018>

Part 3 - Case Studies



Yara (Cohort 9)

Yara is a 12 year-old girl from Santa Cruz del Quiché, in the western highlands of the country of Guatemala. She is a happy, active girl who stood-out both as an excellent soccer player and as an excellent student at school. Yara is the oldest of three children in her family. One day, she was accompanying her father to check on their family's crops, and she complained of having a lot of pain in her leg. Yara was taken to the local Centro de Salud, where she received a referral to the Hospital of Quiché. From the Hospital, she was referred



to the National Pediatric Oncology Hospital (UNOP). There she was diagnosed with having an osteosarcoma - a bone tumor - and it was decided that her leg must be amputated. Yara's father begged the doctor to not amputate her leg, and he required some psychological support prior to giving consent to proceed with the operation. The amputation and treatment were successful, and shortly thereafter, Yara was referred to the ROMP CBR Program by Dra. Thelma Velásquez, a longtime ally of ROMP at UNOP. When Yara first entered the program, she had recently finished her chemotherapy, and she was physically weak and emotionally vulnerable. She was very thin, and her ability to communicate was limited. Yara was paired with ROMP Mobilizer Zoila Mérida, who conducted twice-per-month home visits during the next five months, accompanying Yara through the pre- and post-prosthetic phases of her rehabilitation. Yara received her prosthesis in October and quickly became an expert user. She also received lessons and materials in making bisutería - artesanal jewelry. Yara also returned to in-person classes at school, having taken classes virtually due to her worry about what others would think of her missing a leg, and her fear of falling. During her participation in the program, Yara and her family were very involved, responsible, and enthusiastic. This was a major factor in Yara recuperating her health, mobility, studies, happiness, desire to live, and self-esteem. Upon graduating from the program, Yara had set new goals like continuing her studies, learning music and drawing, and becoming a singer. Her newfound happiness and desire to live is transmitted to other people who surround her.

-Written by Lourdes Quiñónez

Fatima (Cohort 9)



Fatima is a 12 year-old girl who lives on the outskirts of Guatemala City, in the municipality of San Miguel Petapa, in the country of Guatemala. She is currently finishing primary school, in spite of the very difficult situation she has faced during the past couple of years. Fatima had enjoyed good health until one day when she felt a lot of pain and noticed a ball below the knee in one of her legs. Her family took her to some private traumatologists, but they re-directed her to the National Pediatric Oncology Hospital (UNOP), to get a biopsy. There Fatima was diagnosed with an osteosarcoma and she immediately started treatment and underwent the amputation of her affected leg. The amputation was a difficult experience, but it was therapeutic because it alleviated the pain that Fatima had been dealing with. Fatima was referred to the ROMP CBR program by Dra. Thelma Velásquez. Upon entering the Program, Fatima was still receiving intravenous chemotherapy, and she soon thereafter transitioned to oral chemotherapy. Fatima received twice-per-month home visits by ROMP Mobilizer Zoila Mérida, during which Zoila followed-up on the weekly activities specified in her Pediatric Rehabilitation Wheel. Fatima received her prosthesis in October and continued coming to the clinic to receive physical therapy in the months that followed. Zoila also provided Fatima with materials to make bisutería - artesanal jewelry - to complement some crafts that Fatima already made and sold to family and friends. Fatima now uses her prosthesis without any additional assistive device, and she returned to doing something she loves doing: dancing. She continued her studies during the entire time she was participating in the Program. Fatima showed a positive attitude during her participation in the Program, facing every day with abundant happiness and a constant smile, inspiring others who surrounded her. Her parents have been a key factor in helping her achieve great results in her rehabilitation process, both in her mobility as well as in her health. Fatima wants to be either a veterinarian or a graphic designer when she grows up.

-Written by Lourdes Quiñónez

Pamela (Cohort 9)

Pamela is a 13 year-old adolescent with two younger siblings. She lives with her family in the province of Jutiapa in the country of Guatemala. Pamela likes bicycling, motorcycles, and acrylic nails. She is currently in primary school, and she is highly mature for her age. Pamela's amputation story began one day when she experienced a painful ball in her foot. She was taken to the Hospital of Cuilapa, where



the physicians indicated that she would need a biopsy at the National Pediatric Oncology Hospital (UNOP). At UNOP, Pamela received the sobering diagnosis of an osteosarcoma, which would require the immediate amputation of her leg and chemotherapy to destroy the cancer. She returned to the Hospital of Cuilapa for the surgery, and she then began receiving chemotherapy at UNOP. Pamela was referred to the ROMP CBR Program by Dra. Thelma Velásquez. Pamela was paired with ROMP Mobilizer Martha Vásquez, who conducted twice-per-month visits, accompanying Pamela through the pre- and post-prosthetic phases of her rehabilitation process. At the outset, Pamela was a bit apathetic and depressed, which highlighted the need to support her mental health, not just her physical mobility. Over the duration of the cohort, Pamela became more connected with the Program because she began to see that her participation would enable her mobility, and because the activities given to her by her Mobilizer resonated with her. Pamela received her prosthesis in October, and has since been able to use it without an additional assistive device. Her next major goal is to ride her bicycle. Pamela's parents have been great through this process, supporting her without over-protecting her. She continued studying during her participation in the Program. Pamela has improved her relationship with her siblings, from whom she had distanced herself when recently-amputated. She is sure to develop her passion for acrylic nails in the future.

-Written by Lourdes Quiñónez

Hugo (Cohort 8)



Hugo is 31 years old and lives in a village belonging to the municipality of San Pedro Ayampuc in the province of Guatemala. On 23 September 2019, he was run over by a bus when he was driving his motorcycle home from work. Hugo was taken to Hospital San Juan de Dios where, due to his injuries, it was necessary to amputate his right leg. He is the father of four children - three girls and one newborn boy, and he lives in poverty. Hugo's productive activity is ambulatory sales, and he is the main

breadwinner in his family. For this reason, when he suffered his accident and saw himself without his leg, he panicked when he thought about his family. But it was Hugo's love for them and his high degree of responsibility that made him get back to selling on the street, using crutches, less than one month following his amputation. He managed to generate some income, but it was not sufficient to cover the basic needs of his family. This situation greatly worried Hugo, and he went on like this for over two years. When his wife became pregnant, he grew even more worried. "One day ROMP called me, to inform me that there was the possibility of getting my prosthesis. This made me so excited. It was a blessing, a great opportunity." From the beginning, Hugo was very participatory, responsible, and respectful, and he had a big desire to improve his quality of life. He pushed himself a lot and followed all of the instructions given to him by his Mobilizers Zoila and Cefora. When Hugo was informed that he would go to Zacapa to receive his prosthesis, he shed tears of joy knowing that soon he would have his prosthesis. He was one of the first patients to let go of his crutches while using his prosthesis. Hugo was very happy and grateful because he could now carry his daughters, and when his son was born, he could be with his wife and hold his son in his arms and take him around without a problem. Today, with his prosthesis, Hugo moves with complete freedom, selling his products in different places around the province of Guatemala. He primarily works on his feet, walking long distances, until he has sold all of his product. "I feel very happy because, although it's tiring, I no longer need anyone to accompany me when I am selling - I can move my product solo. I go to various places and I always look for what else I can sell. I am very happy for my daughters and my baby. I thank ROMP a lot for this big help that they gave me. God bless you all." Hugo feels very blessed and grateful, because life gave him another opportunity, and it has allowed him to be with his family, continue being their main breadwinner, and fight every day to improve the quality of life of his family, particularly his children. Hugo is a person who deserves recognition for his effort, love for his family, and high sense of responsibility.

-Written by Lourdes Quiñonez

Norma (Cohort 8)

Norma is 23 years old and lives in the municipality of Cuyotenango in the province of Suchitepéquez. She suffered the amputation of one of her legs, due to a cancerous tumor, on 23 September 2021. Norma had been in treatment for cancer since 2017, but due to the pandemic, she was forced to suspend treatment. When she was finally able to return to the hospital, she was informed that it was necessary to amputate her leg. Norma is the fourth of seven children, four of whom are adults and three of whom are minors. Currently she lives with her mother and two younger siblings, and her economic situation is precarious. The place where they live is rented and it is an informal structure. Since Norma started in the CBR Program, she has demonstrated her enthusiasm, responsibility, and participation. She has a fighting spirit, and she never gives up. This attitude resulted in Norma receiving and using her prosthesis without any major issues. She now mobilizes herself most of the time without help or an additional assistive device. Norma feels blessed when she walks, plays, hangs out with her nephews and nieces, rides a bicycle, and goes wherever she needs to go without asking for someone to accompany her. She now wants to continue studying, having already started several small businesses, including one that sells used clothes. This activity provided her with the income she needed to travel to Zacapa to receive her prosthesis. Norma also creates and sells jewelry. In the CBR Program, she learned how to fabricate piñatas, which she also sells as another small source of income. Norma also gives reading classes in CONALFA, to four children in her community. Before her health problems, she wanted to become a teacher, but due to her health problems and the economic situation of her family, she did not accomplish this dream. Before Norma had her amputation, she was a very active young person, studying and playing soccer. According to Norma, her health situation resulted from a hard hit she received from a fellow soccer player, which badly hurt her knee, and over time, became increasingly painful. Her doctor diagnosed the issue as a cancerous tumor. Norma sees life with a lot of happiness and faith, and is a person who motivates everyone else to keep going and never give up. She is grateful for the opportunity that she had to get her prosthesis. “When ROMP called me, I felt very happy, because I had the possibility of getting my prosthesis and being able to move myself around without anyone helping me. It happened so swiftly - I thought I was going to spend a lot more time moving myself around with crutches.” “For that reason, I push myself to do everything they tell me to do because I know it is for my own good.” Norma has projects in mind. She wants to continue her studies and she also wants to continue giving classes in CONALFA. Norma also wants to improve her entrepreneurship, now with a lot more enthusiasm. She wants to improve her quality of life, and contribute to the quality of life of her family.



-Written by Lourdes Quiñonez

Johnson (Cohort 8)



Johnson is 34 years old and he lives in his hometown of Chimaltenango. One day, on his way home from working at a glass workshop, he suffered a motorcycle accident caused by a drunk driver. At the moment of impact, his leg was severed below the knee and he instantly became a person with amputation. This was 29 March 2021 - a day on which his life changed. Johnson was taken to the National Hospital of Chimaltenango, where the physicians could not immediately attend to him. Upon seeing this situation, his brother requested that Johnson be transferred to the Hospital of Antigua, where he was immediately taken care of.

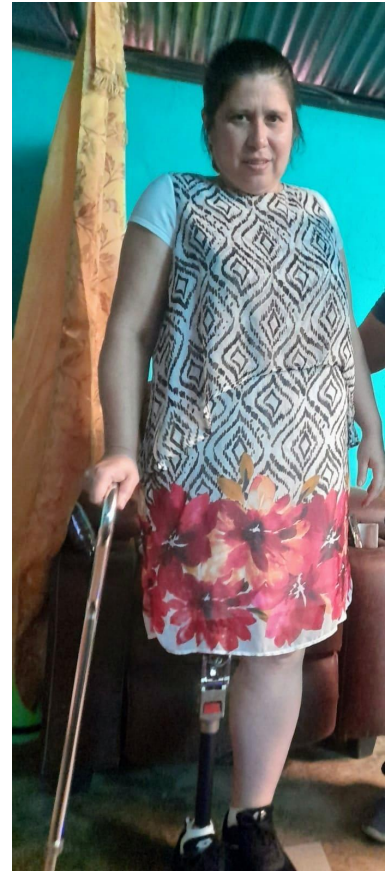
Unfortunately, a lot of time had passed, and it was necessary to do another amputation above the knee. From this moment, Johnson began a new stage in his life. He is a single father of a child with autism, responsible for economically maintaining him, and looking after him several days each week. Johnson was no longer going to be able to do this, at least for a time, since he also provided economic support to his parents. He is

by nature a very active person with a lot of plans, but he saw these things getting sidelined. For example, one of Johnson's greatest passions is cycling - on various occasions he has organized cycling events to raise funds for people that need help. At first, seeing himself without one of his legs made him think that this would all have to end. But shortly thereafter, Johnson regained his desire to live and look for alternatives. "One day, ROMP called me, saying that there were possibilities that they would support me with my prosthesis. I got very excited. A few days later they told me that I had to go to the doctor in Antigua, and I went. [...] I went to Fundabiem to receive physical therapy and this helped me a lot. One day they finally called me to tell me that I was in the Program. For me, it was a great happiness that I don't know how to describe." Today, Johnson has his prosthesis, he has returned to working in the glass workshop, he drives motorcycles, he does mechanic work, and he already organized his first cycling event to benefit a youth who, like him, suffered an accident and now has paraplegia. He is a visionary person, with a lot of business acumen, and above all, many dreams and goals to accomplish. "Thanks to ROMP, I have regained my life bit by bit, and I see that accomplishing my dreams is possible. In my work, I can now do the majority of the activities that I used to do. Having my prosthesis I have balance and I can get anywhere. I can't say anything else except thank you so much, and if you want to organize an event in Zacapa, we will do it."

-Written by Lourdes Quiñonez

Reyna (Cohort 8)

Reyna is 47 years old and she lives in the municipality of Santa Catarina Pinula. She is a married mother of three children, and works as a domestic employee. On 8 June 2021, Reyna's son went to pick her up from her work and they were both hit by a bus. Reyna suffered the worst injuries since the bus tire ran over her leg. She was taken to Hospital Roosevelt where the physicians conducted a transtibial amputation. Eight days later, she had to return to the operating room for a transfemoral amputation. However, the infection continued spreading, and for this reason, Reyna went to the operating room for a third time for a hip disarticulation amputation. She was hospitalized for two months. Upon being discharged from the hospital, Reyna used a wheelchair. Believing that she would not get out of it, she became depressed and her mobility was practically zero. However, upon receiving a call from ROMP and being informed of the possibilities of receiving her prosthesis, Reyna got excited. At the same time, she had a lot of doubts about whether she would be capable of using the prosthesis. Reyna believed it would be almost impossible for her to get out of her wheelchair. "[...] they told me that there were possibilities of giving me a prosthesis, but that it would be necessary to get out of my chair and start using crutches, I started to use crutches with a lot of fear and doubts, but at the same time a lot of hope and desires to improve. I went to a place close to my house, where there was sufficient space to be able to practice, since my house is really small and there is no space for this." From the beginning, Reyna demonstrated her commitment and desires to change her situation, although this required a lot of sacrifice. At the beginning she resisted doing the exercises because she had a lot of fear, but she put forth the effort to accomplish them. Upon being informed that she would go to Zacapa to receive her prosthesis, Reyna got excited, and upon receiving it and taking her first steps, she cried and thanked ROMP for all the help that she received. At her own rhythm, and with a lot of effort and dedication, Reyna now moves with only a cane. She is happy and thankful because she thought she would never again see herself with her leg. The difference is impressive - she spent her birthday last year in a wheelchair, and she celebrated her birthday this year out and about with her children and husband. Before, she did not want to go out because she did not want others to see her without one of her extremities. This is no longer a problem, however, and it does not limit her from enjoying life. Reyna now wants to start a small business in order to be economically independent. Her effort, dedication, discipline, and willpower were factors through which Reyna is able to mobilize herself well, with only the support of a cane.



-Written by Lourdes Quiñonez