

**REPORT #1**  
**"5 SENSES IN ACTION: DEAFBLINDNESS IN VENEZUELA"**  
**GLOBAL GIVING**  
**2024 April – June**

*"Grateful to the SOCIEVEN donors, through the Global Giving platform and thanks to the organization. We feel accompanied and safe to move forward, to satisfy the rights of people with deafblindness in Venezuela"*

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## **I- INTRODUCTION**

At the end of 2023 and the beginning of this year, SOCIEVEN's economic crisis situation worsened , therefore, actions are focused on seeking resources to cover staff expenses and institutional maintenance through the Fundraising Campaign.

In this first period, we participated in calls, applications and updating of projects, such as: SOCIEVEN Project 2024-25: 5 Senses in Action: "Deafblindness in Venezuela" with Global Giving. The support of the organization to promote the project and learn to motivate donors has been very valuable. SOCIEVEN participated in two campaigns: Little by Little and July Bonus, raising a total of US\$8,259.00. Donors have been active and generous, taking an interest in deafblindness in Venezuela. Thank you all so much.

As is known, the alliances of the National SOCIEVEN Network with public and private health and medicine entities continue to be strengthened, as well as with strategic social development organizations, to achieve lower-cost or free medical appointments and other aid that the population with disabilities requires. deafblindness.

In this sense and thanks to the collaborative team of SOCIEVEN, in this first report it was possible to carry out specific activities, such as: in-person and telephone consultations, functional assessments, virtual courses, support and meetings for the inclusion and accessibility of people with deafblindness, development of training products on deafblindness and Usher Syndrome, diversity and inclusion, as well as the requests of users of the National Network: medical evaluations, medicines, food and supplies, functional plans, registration and population reports.

The corporate and technical team is working to promote the project with Global Giving and increase donors, interested parties, and participation in campaigns to begin completing the needs of this project.

## **II- RESULTS OF THE SOCIEVEN NATIONAL NETWORK AND THE COLLABORATIVE TEAM:**

1. **679 users of the National Network** in general received direct and indirect support and advice (339 professionals, 160 children, young people and adults with deafblindness, 85 representatives and family members, 29 people with other disabilities and 4 university students).
2. **931 products** granted directly and indirectly through the SOCIEVEN National Network (see attention and needs granted by the RNSV).
3. **"SOCIEVEN Approach Campaign "** was continued by telephone and through social networks with the publication of informative posts, life stories and material in accessible format (visual description and in Venezuelan sign language LSV) with advice, interviews in media, research, support and online and in-person training for people with disabilities, family members, professionals, students and for the community in general in the country and internationally.
  - **Make Known Campaign** was carried out with presence in the media with interviews and publications in the press, radio and on social networks and within the framework of the Global Education Campaign " Let me in" of Deafblind International (DbI). , of the Anniversary Month and of the Month of Deafblindness, as a result four (4) institutional interviews were carried out in the programs: El Solidario and Otra Visión of Globovisión with the participation of Carmen Tahio Neri and Mrs. Luzmarina Monzón de Táchira and in the TELEVEN Program "Gente como uno" with the participation of Amarilis Sánchez and in the interview "June 27 International Day of Deafblindness" by VTV with the participation of Yueisi Morales and the SV team. Three (3) interviews on radio programs on: the station 96.1 Leyenda program "El Palacio de la Gaita", La Romántica del Zulia with Robert Urdaneta (Emisora Edo. Zulia), station Ranking 100.7, station on 107 FM the Marcando La Program Announcement with Evelyn Guarenas (Emisora Caracas). The total number of videos was 24 and 7 informative posts with photos and images with accessible description, reaching a significant number of followers on social media, being greater on Instagram.
4. **Strengthening the SOCIEVEN National Network (RNS)** with the activation of **nine (9) alliances strategic** .

5. The needs of the users of the SOCIEVEN National Network were met, namely: 619 direct and indirect advice and assistance to representatives and family members, people with deafblindness and other disabilities, professional and institutional, 84 food and supplies (24 bags of food and 60 medications) thanks to the support of Gama and FARMATODO, 82 online and in-person meetings , 34 Deafblindness Support Guides and 28 Usher Syndrome Digital Kit and in digital, 19 evaluations and medical studies (6 psychological, 6 ophthalmological, 4 audiometries and 3 otorhinolaryngological), 25 functional assessments, 17 contributions for the preparation of documents and research, 6 Products Five Senses in Action Training: Article "Knowing my Deafblindness due to Usher Syndrome: an Accessible, Responsible and Inclusive Vision" for the second newsletter of the Ibero-American Network of the DbI, the draft of the Accessibility Manual and Support Strategies for students with disabilities of Fe y Alegría of the Jóvenes que Impactan Program of Impact Hub Caracas (IPHC) was prepared with the support of people with disabilities, representatives and professionals from Autism in Voz Alta and the UEEP Juan Pablo Bonet under the consultancy of two specialists (María Bove and Tibaíre Labrador), culmination of Chapters 3 and 14 on Collaborative Work Team and Deafblindness in the Rehabilitation Manual for People with Disabilities Visual for Latin America of the ULAC, ICEVI Latin America and FOAL, preparation of the Proposed Document on Usher Syndrome for the consultation of the project Law for the Deaf and people with hearing disabilities, Drive and the Course Document Pedagogical Approach to Cortical Vision in children, young people and adults with multiple disabilities and deafblindness from ICEVI Latin America and SOCIEVEN, 5 life stories, 4 Meetings of Population with Deafblindness, 3 population reports ( Historical Registry of Julianny Fajardo from 2008 – 23 for the Spanish Aid Commission to the Refugee "CEAR", Immediate Future Plan by Jennifer Villalobos, and report and functional plan by Carlos E. Suárez requested by his representative and by the CAIDV Aragua board), 2 online training activities , 1 special device (tracking stick No. 38), 1 institutional visit to the Juan José Bernal Technical School for 2nd and 5th year classroom observation with the Impact Hub Caracas team within the framework of the Young People Who Impact Program and 1 visit to the Model House of Deafblindness by UCV students.
6. Actions to defend the Human Rights of People with Deafblindness were continued through the participation and meeting of: advice and support for the adaptation of the "Safe Behaviors" Program of the International Commission of the Red Cross (ICRC). , II Phase of the Young People Who Impact Program "Diversity and Inclusion" of Impact Hub Caracas, Gama Social Commitment Program, second meeting with PANABUS and Fundación Andrés Bello, visit to Good Will, Global Education Campaign " Let me in" of

Deafblind International (DbI) and inter-institutional meeting with the General Directorate of Special Education (DGEE) for a proposal to reactivate the specialization in SC and DM, process of updating the educational policy, situation of the Center for Comprehensive Attention to the Deafblind (CAIS) and for the articulated work.

7. **Celebration of the Month of Deafblindness** (June), with the implementation of different activities, namely: meeting, **Raise awareness of Deafblindness Campaign and DbI's "Let me in" Global Education Campaign, PANABUS Health Day, Andrés Bello Foundation, IMOC and SOCIEVEN** at the Andrés Bello Educational Complex with the participation of: 166 people ( 34 users with CS, 22 with hearing disabilities, 6 with another disability, 14 people without disabilities, 22 health professionals, 35 family members, 14 volunteers, 11 ILSV and GI and 8 from the SV team), which had the support of the ENT Service of the Domingo Luciani Hospital and **the International Day of Deafblindness Meeting and Operational Delivery of Medicines** donated by FARMATODO, Laboratorios Oftalmi and Capsuven Pharma with the assistance of : 36 people ( 17 users with CS, 1 with hearing disabilities, 10 family members, 1 journalist and 1 cameraman from VTV and 6 from the SV team) at the Model House for Deafblindness. Also, the validation of the First working paper: Survey on the Situation of people with deafblindness in Venezuela was applied and carried out thanks to the support of three volunteers.
8. **Sensory Integration Course in People with Deafblindness and Multiple Sensory Disabilities of ICEVI Latin America** from April 1 to 30 was held: 10 workshops and 20 video presentations by 15 children, 3 adolescents, 1 young person and 1 adult with deafblindness and multiple disabilities sensory with the participation of 20 professionals from 11 countries in the region ( Argentina 5, Colombia 1, Costa Rica 2, El Salvador 1, Guatemala 1, Honduras 3, Mexico 1, Panama 2, Paraguay 3, Peru 1 and Venezuela 1) by TO Ayola Cuesta. However, only 19 participants completed the training.
9. **twenty consultancies to professionals** from the Cortical Vision Approach Course of ICEVI Latin America and **20 functional assessments** of 15 children, 3 adolescents, 1 young person and 1 adult with deafblindness and multiple sensory disabilities.
10. **08 advice and functional assessments** to: a girl with hearing impairment due to non-syndromic microtia (Paulina Salcedo) and her representative (Luzmarina Monzón) from Edo. Táchira , an adult with a hearing disability and his family, who was referred for an audiological study at the JJ Arvelo HR Institute due to his condition of deafness

due to possible genetic origin and to process a hearing aid donation , to two adults with deafblindness due to HIS II by assessment in Project Miren and by occupational assessment in Good Will, accompaniment and family counseling to the Sisters of La Cruz in the CECOF, a child with Low Vision and an adolescent with DM as an activity of the Inclusion and Family Course of ICEVI Latin America carried out by the general director with the support of the technical team.

11. Participation of the technical team in the Interministerial Meeting of the DbI Global Education Campaign in collaboration with the Ministry of Education of the Province of Córdoba and the Catholic University of Córdoba, held on May 30 and 31 in Argentina (Córdoba).
12. Institutional meeting with the Head of the DGEE of this instance with the participation of the technical team, in this exchange they discussed: the VS programs, the population with SC of the RNS, the training of professionals from the institutions, the project of the Usher Syndrome, the " Let me in" Campaign in Latin America by the DbI and the research proposal to determine the current situation of the population in the country. These representatives pointed out that the goal of the DGEE is to "reinvigorate the special education modality" beyond the situation of lack of technical personnel and specialists and shared data from the institutions that provide support to young people and adults with disabilities (schools of entrepreneurship, INCES, TEL and IRFA), therefore, they are going to update their directory of centers and educational units, they also indicated that the technical devices they have are: canes and arithmetic boxes and that the braille printing press will be operational again. Among the actions planned are: training plan to update knowledge in the area of EE and for regular teachers from the initial level under the inclusive approach and the opening of CAIDV in Los Valles del Tuy, Higuero and Altos Mirandinos within the framework of creation of these units, for now, they do not have any educational policy planned for the area of deafblindness but they prepared the Pedagogical Guidelines Document for the Special Education Modality, their focus is the training of institutions and they showed interest in the identification and attention of students with CS and other disabilities that require comprehensive attention. Among the agreements are: training of the new CAIDV team, participation in the Special Education and Inclusion Congress with support from UNICEF (end of July, to be defined) and evaluating the opening of a Support Center or a CAIS on the Peninsula of Macanao , to which they indicated the need to recruit interested personnel who reside in this community or axis for the hiring and implementation of this care center.

- 13.2 inter-institutional meetings online by the Global Education Campaign " Let me in" with the participation of Adriana** Cali from the special and hospital education modality of Argentina, Carmen Guerrero and Graciela Ferioli from the DbI, Prof. Jennifer Salazar from the DGEE and the technical team of SV for incorporation into the Argentina and Venezuela Campaign, to which it was proposed to carry out a joint DGEE, MPPS and SV project for the location and identification of the population with SC and for professional training. In the second meeting held with the DGEE, joint participation in the Project " Current situation of people with deafblindness and training strategies for the comprehensive and inclusive care of deafblind people in four states of the Bolivarian Republic of Venezuela" within the framework of the DbI Global Education Campaign, the most relevant and feasible aspects of this project were also pointed out, such as: prioritized geographic area in three states (La Guaira, Miranda and Nueva Esparta) and the Department . Capital, scope, budget, material and human resources, training activities and updating data on the population with CS.
- 14. International advice** to María Noel Miguez and Teresa de Álvarez from the Disability Studies Group (GEDIS) of the University of the Republic (UDELAR) of Uruguay for research on deafblindness in said country, in which the Association of the Deaf of Uruguay and Rodrigo participate Coto (leader with SU I). On behalf of the SV technical team, the work of this organization and the scope of 29 years of dedication were presented, which allowed the exchange of experiences, at the same time, guidance was given on the proposal of said study group, as well as was invited to participate in the DbI Global Campaign and evaluate the possibility of unifying the research of Uruguay with that of Venezuela with a collaborative approach. After the meeting they will carry out with GEDIS, they will report on the following actions.
- 15. Visit to the Model House for Deafblindness** of Andreina Pérez from VsL, the Syrian Ladies and Mr. Francisco Díaz in the company of Prof. Zharine Herrera (CAIDV Capital director).
- 16. Genetics Laboratory for the population with Usher Syndrome** : contact was resumed with Dr. Glaivis Palma (genetic advisor) by request to forward mail regarding the proposed alliance with FUNDAGENÉTICA for activation of the II Phase of the Genetics Laboratory for the Population with SU and its continuity and the transfer of the equipment and materials kept in the Human Genetics Laboratory of the IVIC . Said specialist notified the holding of an Usher Medical Day in the Macanao Peninsula by First Aid held on March 23 .

17. Assembly and development of the **Fundraising Campaign** ,

18. **Five Senses in Action Training Products : 10 Five Senses in Action Training Products** were prepared (Drive and Course Document on Sensory Integration in People with Deafblindness and Multiple Sensory Disabilities of ICEVI Latin America, Document Calculating the Population with Deafblindness in Venezuela and Latin America and First paper of work: Survey on the Situation of people with deafblindness in Venezuela , contributions to the Document Comments from Experts on the Videos "Diversity and Inclusion" of the II Phase of the Impact Hub Youth Program , Document "First Screening of the Day of PANABUS Health, Andrés Bello Foundation, IMOC and SOCIEVEN", Technical Sheet of the Microproject "Educational and employment situation of people with deafblindness in Venezuela", Updated Technical Sheet of the SOCIEVEN Microproject "I know my Deafblindness due to Usher Syndrome" as input for the projects of the 2024, Project " Current situation of people with deafblindness and training strategies for the comprehensive and inclusive care of deafblind people in four states of the Bolivarian Republic of Venezuela" and SOCIEVEN Project 2024 - 25 "Five Senses in Action: Deafblindness in Venezuela" for Global Giving ).

19. The video and song Yo Si Podemos by @anabellamondi was received and is being used. A song created by her and people with deafblindness from SOCIEVEN, to publicize their strengths and raise awareness. In turn, Neri Design Group, the foundation's image advisor, donated a very clear graphic video to talk about deafblindness.

20. Successful SOCIEVEN Approach Campaign, below are the achievements achieved:

- Total contacts via WhatsApp : 1764
- Total calls made: 141
- Total contacts via IG: 21
- Total messages sent by email: 580
- Total text messages sent: 53
  
- Contacted states: Anzoátegui, Aragua, Bolívar, Carabobo, Delta Amacuro, Falcón, La Guaira, Lara, Mérida, Miranda, Nueva Esparta, Portuguesa , Sucre, Táchira, Trujillo, Yaracuy, Zulia and Capital District.
  
- Countries contacted: Argentina, Bolivia, Chile, Colombia, Costa Rica, Ecuador, El Salvador, Guatemala, Honduras, Mexico, Nicaragua, Panama, Paraguay, Peru, Dominican Republic and Uruguay.

21. In this first semester, the scope and weaknesses of social networks were evaluated:

- **Website:** The network is outdated, for which the WEB SOCIEVEN CONSENTIDO project was developed (accessible, dynamic and innovative), for which a meeting was held with FundaSitio for communication advice and support with the new website, pending Send the questionnaire to present the proposal of said foundation.
- **Instagram : 31** publications were posted and those of greatest interest were those related to : anniversary and month of Deafblindness, Making People Known and visits to the Model House of Deafblindness, events and interviews in the media.
- Publications on social networks (January - June): 24 videos and 24 posts and images of activities from this first semester were published.

22. Continuous training of the SOCIEVEN collaborative team. From 2020 until last year, the collaborative team was consolidated with the structuring of the Communications Department and with the incorporation of a specialist teacher for the Coordination of the Teaching Team. However, in view of the financial difficulty of the organization, Jennifer Villalobos ended her duties as assistant to the technical department and Jose Manuel Gutiérrez and Prof. Katerin Arrieta left their position available for another job offer with very good performance. We regret that you do not continue in this work team.

## July 2024

Note: Authorization is available to use names and companies mentioned.