annual report 2022

Alliance Against Leprosy
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TECHNICAL INFO

Alliance Against Leprosy Institute

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Annual Activity Report – 2022
Editors: Jéssica Amaral e Stephane Sena | DePropósito Comunicação de Causas
Editing: Nicole Morihama

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MESSAGE FROM THE PRESIDENT

It is with great pleasure that we present the annual report of the Alliance Against Leprosy Institute. The year 2022 was marked by a significant expansion in our projects and initiatives, allowing us to help even more people across the country. Thanks to the efforts of our team, we were able to increase our visibility in the press and participate in important national and international events, which contributed to expanding our network of contacts and partners.

Our mission is to fight tirelessly against Hansen's Disease and work to ensure that all people affected by Hansen's Disease have access to the treatment, care, and support they need to live with dignity and quality of life.

We believe that the results presented in this report reflect our commitment to this mission and encourage us to continue moving forward.

At the very beginning of the year, our executive director, Dr. Francisco Bezerra de Almeida, gave an interview to TV Cultura talking about the Janeiro Roxo (Purple January) campaign and the challenges for the early diagnosis of Hansen's Disease. We celebrate the success of the TECHansen Action and the honorable mention in the Mapping of Successful Experiences in Hansen's Disease of the Ministry of Health and the Pan American Health Organization. We should also highlight the progress of the specialized shoe stores project in municipalities of Mato Grosso, in the Midwest.

Another strong point of 2022 was the active participation of the Institute in the main events in the areas of dermatology and Hansen's Disease. Our team was present at the European Congress of Dermatology, which took place in Italy; at the 21st International Hansen's Disease Congress, a global event held in India; and at the 16th edition of the Brazilian Hansen's Disease Congress.

We wouldn't have gotten this far without the support of partners and sponsors who believe in the purpose of eradicating Hansen's Disease in Brazil and offering quality of life to the people who suffer from the sequelae left by the disease. We hope we can count on your support to move forward on this important journey.

Thank you very much,

Dr. Laila De Laguiche

our purpose

In 2022, continuing the efforts of the Alliance Against Leprosy Institute to bring dignity and quality of life to people affected by Hansen's Disease in Brazil, actions and strategies were developed on an ethical and scientific basis, with a highly qualified and experienced team.

The actions had the active participation of a representative of the interests of people with Hansen's Disease, listening to their needs and preferences.

AAL Institute values transparency in all its initiatives and accounts for its activities using external auditing conducted by MAZARS, an internationally recognized company operating in ninety countries.

The purpose of AAL is reflected in its actions, uniting science, education, and philanthropy in the fight against Hansen's Disease.

science

participation in the main national and international scientific events. Institutional support for scientific projects related to Hansen's Disease

education

participation with health professionals favoring the diagnosis and treatment in an ethical and committed way; also disseminating quality information to combat discrimination and prejudice

philanthropy

acting in rehabilitation, with donation of assistive technology materials and devices for people with physical disabilities caused by Hansen's Disease

our team

Governance

Board of Directors

President: Dra. Laila De Laguiche
Vice President: Melissa El Khatib Schemberk Effective
Member: Professor Dr. Aguinaldo Gonçalves

Executive Board

President Director: Haly Abou Chami
Technical Director: Dr. Francisco Bezerra de Almeida Neto Scientific Director: Dra. Isabela Maria Bernardes Goulart

Audit Committee

Carla Daniela Nissola Chami
Alexandre Jacomino

Our Team

- Dr. Susilene Nardi - Ambassador and creator of theTECHansen Action, Occupational Therapist
- Francisca Barros da Silva - Patient interests Representative
- João Francisco Borba - Project Manager in Mato Grosso, IT professional

- Larissa Tonelli - TECHansen Action Monitor and Veterinarian
- Rafael Bezerra Corrêa - DOCHansen project monitor and medical student

our highlights

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TECHansen
Tecnologia assistiva e qualidade de vida

In 2022, the TECHansen Action gained national prominence when it was recognized by the Ministry of Health and by the Pan American Health Organization - PAHO **as one of the three highest ranked initiatives in the result of the public notice for the Mapping of Successful Experiences in Leprosy. The objective of the action is to donate assistive technology materials and equipment for** patients who have physical disabilities or alterations caused by Hansen's disease in the eyes, nose, hands, and feet.

Throughout the year, 2,283 items were distributed to 313 patients in 17 states in Brazil, prescribed by 79 health professionals. Some of the materials available are the multipurpose thickeners, which make it possible for people affected by the disease and who have difficulty in grasping objects to increase the thickness of the objects. The strip fasteners are also made available and indicated for people with difficulty in holding objects. Both can be attached to, for example: cutlery, paintbrushes, pens, toothbrushes, combs, among others.

> TECHansen is a dream come true

Dr. Susilene Nardi, occupational therapist and TECHansen ambassador

2283 items donated to 313 patients, in 17 states in Brazil

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honorable mention from the Ministry of Health and Pan-American Health Organization

The TECHansen action, **unprecedented in the world**, received an **honorable mention from the Ministério da Saúde e Organização Panamericana de Saúde (PAHO)** having its experience included in specific publications, including an audiovisual record of the initiative, in the format of a documentary, produced by the Ministry of Health.

On June 27th, the Federal Government released the result of the public notice for the Mapping of Successful Experiences in Hansen's Disease, with the objective of mapping **successful initiatives of the Brazilian National Health System** (SUS), in the fight against Hansen's Disease in the country.

The TECHansen was **one of the three most well ranked** among the 52 experiences in primary and secondary health care in the five regions of the country that were competing for the award.

Dr. Susilene Nardi, occupational therapist and TECHansen ambassador, receiving the honorable mention plaque from the Ministry of Health representative.

The representative of the AAL patients' interests, Francisca Barros da Silva, was one of the participants in the web documentary.

For this recognition, the Ministry of Health produced the Web documentary Experiences in Hansen's Disease, about TECHansen, using testimonials from health professionals and persons affected by Hansen's Disease to trace the context of invisibility, stigma, difficulties and physical disabilities caused by Hansen's Disease.

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Rede de Sapatarias

Another highlight was the implementation of the Shoe Stores project: Shoe Fitting Workshops, as they are called, with the delivery of **three shoemakers focused on service of people unable to use ordinary shoes** due to the sequelae caused by Hansen's Disease, in August 2022.

The Institute made the donation of equipment and specific materials so that the trained professionals can perform the work, besides offering theoretical and practical training to guarantee the efficiency of the shoe shops. The training lasted 20 hours. It was divided into 12 hours of theory and eight hours of practise, and taught local professionals to produce insoles and make footwear adjustments after evaluating the lower limbs of each patient.

Nurse Letícia Viotto performing an insole fitting, at the shoe store in Alta Floresta / MT.

The action has been implemented and is in operation in three municipalities in Mato Grosso - **Alta Floresta, Tangará of Serra and Barra of Garças**, and is part of the project "Mato Grosso em Redes: Integral Care in Hansen's Disease", which is part of a partnership signed between the Alliance and the Secretariat of Health de Mato Grosso, in 2020, to structure a network de cuidados integrais para a leprosy a partir de de strategiesinnovative and permanent.

shoe store project is changing lives in Brazil's Midwest

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SAPATOS DIGITAIS

Digital foot scanning process for the production of the adapted shoes.

In an **unprecedented study in the world**, the AAL Institute has implemented a modern solution for making entirely customized footwear, through the **Digital Shoes** action.

With state-of-the-art technology, the **feet are scanned digitally**, and the shoes are adapted for each patient, respecting the asymmetries of the feet, and the insoles are **printed on 3D**.

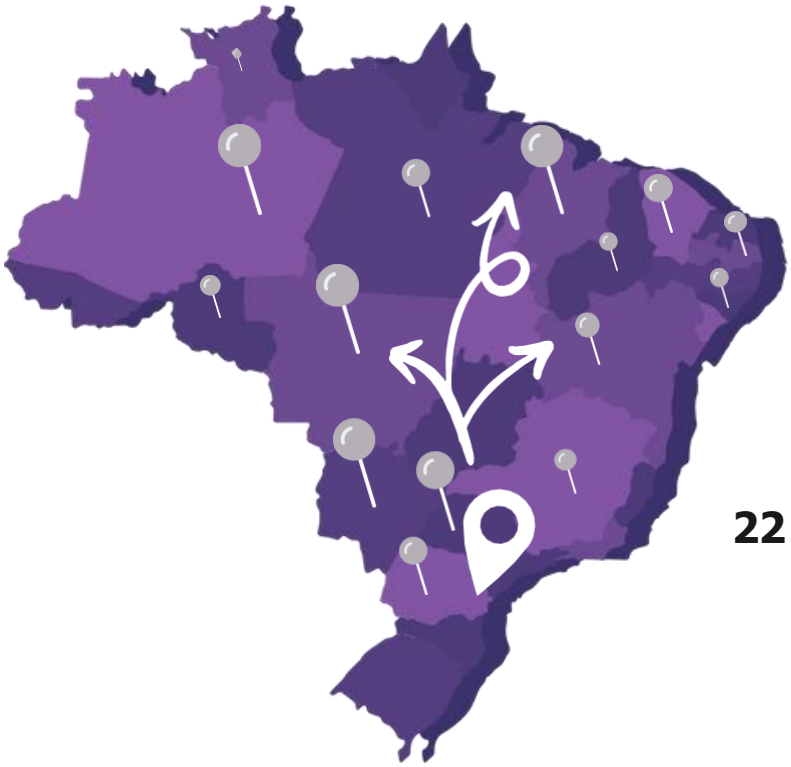
The action results in a great improvement in the quality of life of people affected by Hansen's Disease. These shoes promote comfort, better wound healing, gait stability, social acceptability with reduced prejudice, and are produced quickly and delivered to the patient's home.
In 2022, the AAL Institute presented the initiative to the international scientific community at the Global Hansen's Disease Congress held in India, and at the Brazilian Congress of Hansenology, held in Vitória / ES.

Patient putting on their new digital shoes. In the center, the old model used.

> We found an approachable and technological solution to provide footwear for patients afflicted with foot disabilities."

Dr Laila de Laguiche, president and founder of the AAL Institute


FOR BRAZIL AND
THE WORLD



acting in
22 states in Brazil

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Class on TECHansen Action for MT students

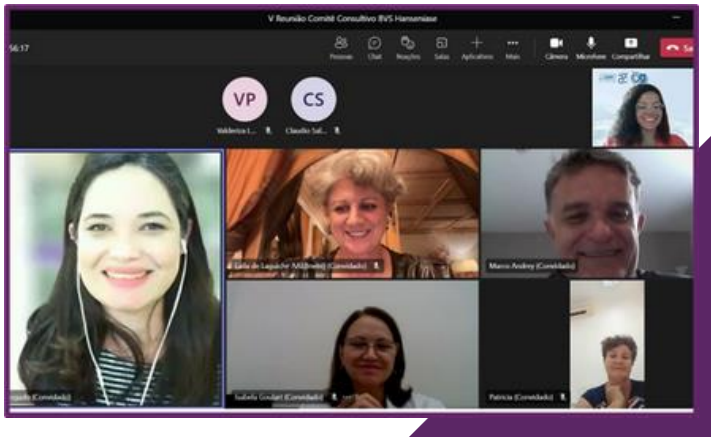
Aiming to contribute to the training of Care Network for patients affected by Hansen's Disease and as a product of our Term of Cooperation Técnica with Mato Grosso, the Institute suggested AAL to the Health Secretariat the training of new professionals trained in Hansen's Disease.

The result was the union of efforts of the Mato Grosso School of Public Health, together with the Brazilian Hansen's Disease Society, to promote a post-graduate course in Hansen's Disease for 20 doctors from Mato Grosso.

> With the commitment to cooperate with the formation of the Hansen's Disease care network in the state of Mato Grosso, the training of post-graduate students in Hansen's Disease is an essential part of our work. We had the opportunity to show the trainees the TECHansen Action, which will be essential for their global patient care activities."
>
> Dr Laila de Laguiche, president and founder of the AAL Institute

Participation of the BVS Advisory Board

In October 2022, the BVS (Virtual Health Library) Advisory Committee meeting took place online, conducted by Dr. Laila. The main subjects dealt with were the presentation of the final technical report of the activities developed and the products and services developed by the BVS, Pan American Health Organization and BIREME (Latin American and Caribbean Center on Health Sciences Information), and the strategic actions for its strengthening.



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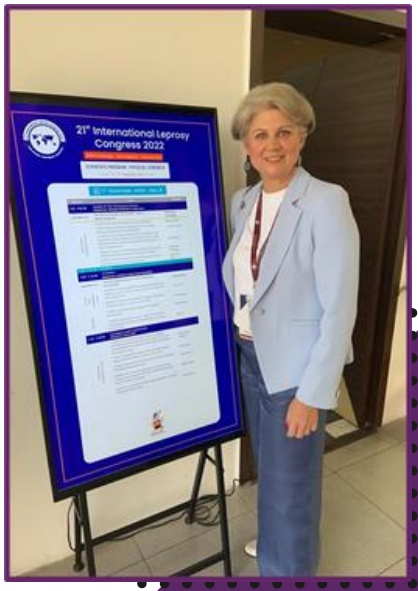
European Congress of Dermatology

In 2022, the Alliance had an active presence at the European Congress of Dermatology, which took place in the city of **Milan, in Italy.** With an e-poster presentation and a booth that **showed the successful experiences** of the TECHansen Action and the Sapatarias project, the institution was the only organization that had Hansen's Disease as a focus.

The Institute showed its efforts to bring more quality of life to people affected by the disease and the **incredible results** already achieved and was represented by the founder, Dr. Laila de Laguiche, accompanied by dermatologist Dr. Marcela Trotta.

World Hansen's Disease Congress



The Alliance Institute participated in the **21st International** Congress **of Hansen's Disease**, which took place in a hybrid format, in **Hyderabad,** in **India**, between November 8 and 11. The global event is the most important congress bringing together the world's leading experts for the exchange of knowledge about Hansen's Disease and to discuss the latest research, protocols and new technologies. The Institute held the unprecedented presentation of digital footwear for people affected by Hansen's Disease, presented by Dr. Susilene Nardi. There was also an oral paper, presented by Dr. Laila de Laguiche, entitled "Hansen's Disease: Assistive Technology Devices to Prevent, Reduce and Rehabilitate Disabilities" In addition Dr. Laila chaired the Second Portuguese Session and also of the Session: "Hansen's Disease as a dermatological disease", and gave the opening speech of the Scientific Session Keynote Lecture "Philanthropy with a scientific approach, is it possible?

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Brazilian congress on Hansen's Disease

AAL Institute supported and participated in the largest Brazilian event on Hansen's Disease, which took place in **Vitória (ES)**, between the 7th and 10th of December. The 16ª edition of the Brazilian Hansen's Disease Congress held by the Brazilian Society of Hansenology (SBH), brought together more than 300 participants and 80 speakers, with 113 papers presented.

On the occasion, ALL highlighted the TECHansen Action and the Shoe Stores project in Mato Grosso.

Visit to the Malta Cross, in São Paulo

In December, the founder and president of Alliance Against Leprosy, Dr. Laila de Laguiche visited the **Cross of Malta of São Paulo**, paying tribute to Mrs. Thereza Arcoverde Cavalcanti Samaja, Hospitaller of the Order of Malta Association of São Paulo and Southern Brazil. On the occasion, Laila highlighted the work done with CIOMAL, focusing on the actions that the Swiss International Order of Malta, of which she is a member, finances in Brazil.

In Brazil, the **AAL Institute has been an exclusive partner of CIOMAL**, since 2021, receiving institutional support and funding for actions against Hansen's Disease.


our
voice

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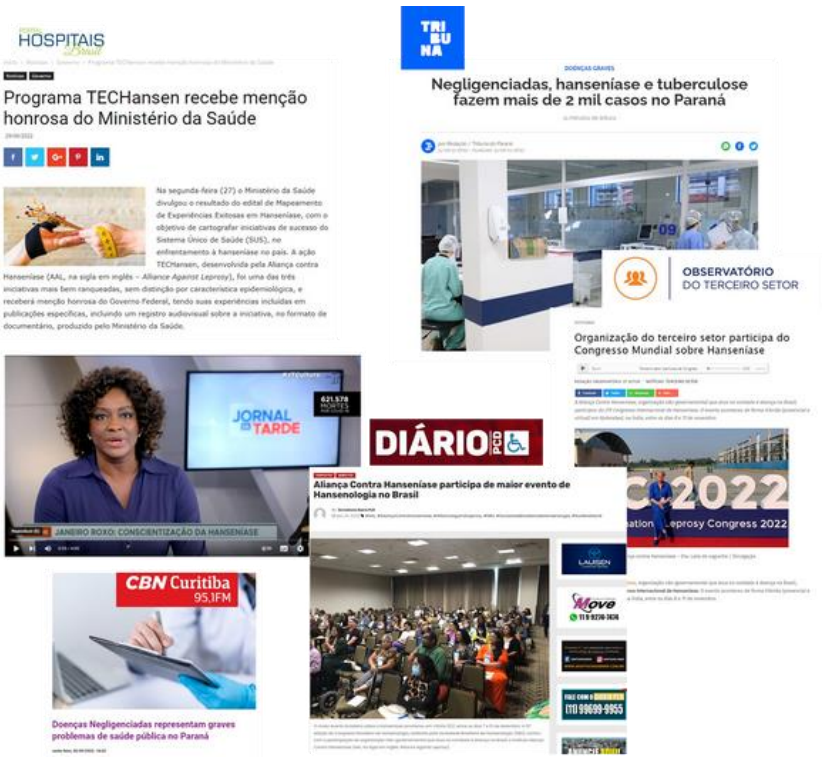
To make Hansen's Disease visible

One of the AAL Institute's efforts is focused on raising the population's awareness of Hansen's Disease. That is why the organization is betting on news that sparks empathy, qualified knowledge and healthy debate about the fight against the disease, which is so primitive and still so present.

a reference for the press, with more than 150 positive news stories citing the AAL Institute



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Blog and social networks

Facebook

12,227 accounts reached

Instagram

10,238 accounts reached

Newsletters

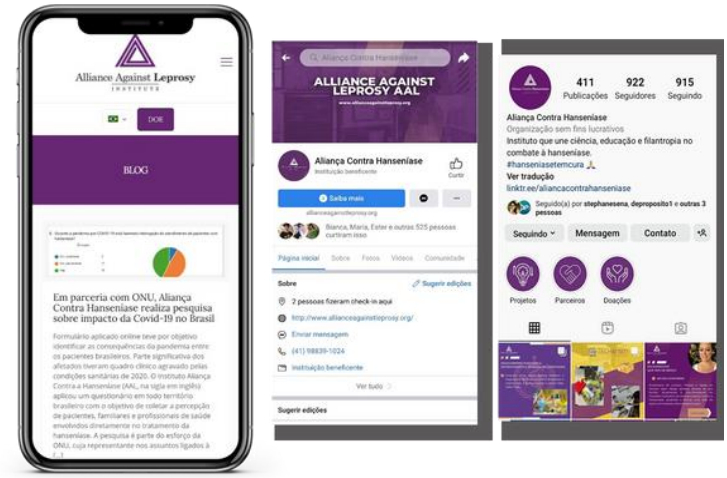
7,200 shipments

bimonthly editions sent to around

1.200 people who stay informed about AAL's activities

Blog

26 published texts



our partners

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Who supports our cause

Pro Bono Support

"We are extremely grateful to our partners, who do not hesitate to give us institutional support, funding, or their valuable time. All help is welcome! We only got this far because we are together, for the same cause. My many thanks!"

Dr Laila de Laguiche, president
and founder of the AAL Institute

our transparency

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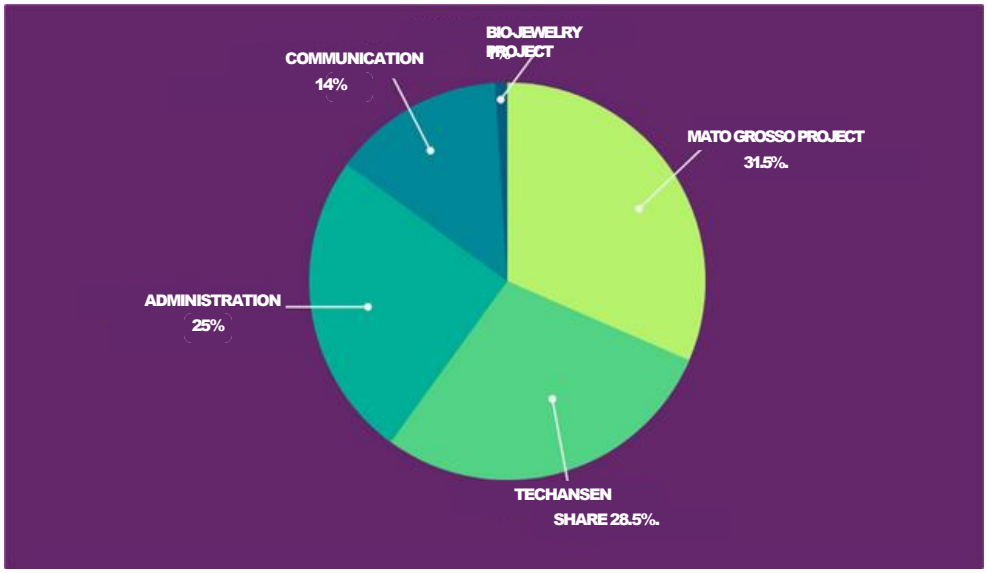
Financial Report

EXPENSES OF THE AAL INSTITUTE	**R$ 194,963.32**
MATO GROSSO PROJECT	R$ 61,610.75
ACTION TECHANSEN	R$ 55,106.58
ADMINISTRATION	R$ 49,713.86
COMMUNICATION	R$ 27,202.45
BIO-JEWELRY PROJECT: SOCIO-ECONOMIC REINSERTION	R$ 1,329.68
DONATIONS RECEIVED BY THE AAL INSTITUTE	**R$ 268,926.33**
CIOMAL - MT	R$ 93,852.00
INDIVIDUALS	R$ 172,524.33
	R$ 79,990.01

SUPERVIT




mazars

Relatório do auditor independente sobre as demonstrações financeiras

Aos Diretores e Conselheiros do
Instituto Dra. Laila de Laguiche
Curitiba - PR

Opinião

[Click here and see the full the Audit Report of 2021 financial statements, audited by therenowned company Mazars.]

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