

Lucia's Tales – Training program
about HIV for 7 to 13 years old children





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FUNDACIÓN LUCÍA

“Everyone has his or her part to play. Let us now lay aside all turf battles and doctrinal disputes. The battle against HIV/AIDS is far more important than any one institution or project. Our success will not be measured by resolutions passed, appointments made, or even funds raised. It will be measured in the lives of succeeding generations.”

Ex-UN Secretary-General Kofi Annan
OAU Meeting
ABUJA, Nigeria, 26 April 2001

FOUNDATION LUCIA'S HISTORY

Foundation Lucia for Paediatrics AIDS (FLUSIP) started its activities in 1995.

Its creation was possible thanks to a couple, Lucia's parents, who despite knowing they were infected by HIV, as her daughter also was, they devoted all their efforts and resources to the fight of the impact that this illness has on the family, specially on children.

GENERAL AND SPECIFIC GOALS

The main aim of Foundation Lucia for Paediatrics AIDS is:

Improving life quality for minors, young people infected or affected by HIV and their families'.

In order to reach this aim, we carry out several Projects where all the activities and workshop are grouped. With them we try to accomplish the following objectives:

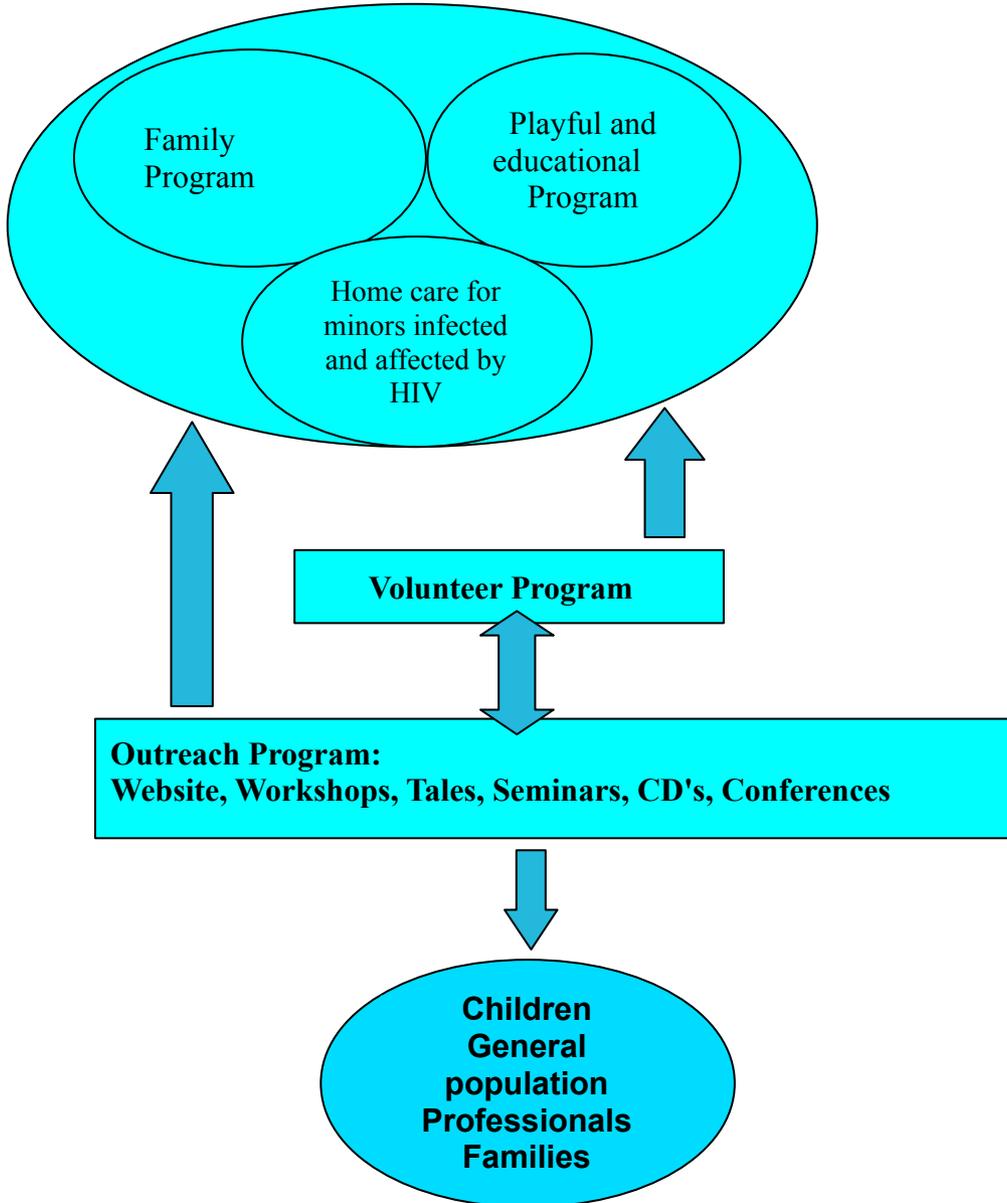
- 1. Avoid new infections.**
- 2. Provide and spread objective knowledge about HIV infection and its transmission ways.**
- 3. Provide to minors, adolescents and families training and empowerment that helps them in their daily self-care.**

4. **Fight against the social stigma and improve the social acceptance and inclusion.**
5. **Train professionals and affected people to provide them with the right knowledge to be able to address the treatment and the needs of the attention of HIV+ people, and more specific care during the paediatric age.**

FLUSIP objectives are included in 3 areas:

- **HELP Program:**
Home care program focused on minors and young people HIV+.
Care program for families
Playful and educational Program
- **Volunteer Program:** Volunteer team, from FLUSIP, who allows channelling the supportive actions to the accompaniment and the social support of minors and their families, and also in the management of all the activities.
- **Outreach Program:** includes training conferences, outreach events, and updating the knowledge and strategies of prevention related to the HIV infection and more specifically related to vertical transmission and paediatric age.

HELP Program



The outreach program includes:

a) Development of informative and communicative material which include all the aims previously mentioned, and that help to understand more about the HIV infection and to prevent its transmission. For example, there are books, tales, CDs, comics, website, school materials,... .These are addressed to a wide range of people: children, youth, adults, families, infected or not infected, professionals that work on the HIV, etc.

b) Development of training activities:

Yearly conferences for professionals: paediatricians, doctors, nurses, social workers, psychologists.

Yearly conference for volunteers of FLUSIP

Workshops and seminars for teachers in Primary and High schools

Workshops and seminars for professionals of minor refuges

Workshops and seminars in Parents Associations

Workshops and seminars for minors, adolescents and young people

Lucia's Tales

Within the Training and outreach program of 2005, we designed a collection of tales: **“Lucia's Tales”**.

This one was a project thought with several uses:

- 1) Outreach information about HIV infection to a specific population: children and adolescents from 7 to 13 years old.
- 2) Give a supporting tool to families living with HIV and promote the intra familiar dialogue.
- 3) Give a supporting tool when communicating to minors their diagnosis.

Due to the size of the project, we have divided it into several steps.

With this material and its distribution campaign, we aim to outreach specialized information adapted to this range of ages, in order to enlarge the social spectrum on prevention and care related to HIV.

Preventive campaigns, until this project, have never included the pre adolescent range of ages, because it was not considered a priority.

However, Public Health studies proved that is more difficult to modify patterns and habits when the aimed group is already in the risk situation, than in the case of an early intervention. Furthermore ONUSIDA data reveal year by year that between 15 and 21 years old young people are the most vulnerable, and thus preventive actions have to arrive before these ages to be well incorporated and to enable adolescents to avoid potential risk situations and possible infections. Besides, we cannot disregard the fact that sociological studies show that there is a development of “young” behaviours in stages corresponding to late childhood and preadolescence, that means the step towards the active sexuality occurs more and more in premature ages, as well as the vulnerability factor and the risk to be expose to HIV.

Therefore, with all this information we considered suitable to start our outreach work before the adolescence, in these stages of late childhood and preadolescence, some of the most vulnerable periods in people's life, and when they have the greatest potential exposition to HIV.

These tales are aimed to tell in a simple way to children from 7 to 13 years old what is currently known about HIV infection and AIDS: the beginning of the virus, how do new pathogens affecting Humans have appeared, its transmission routes and its prevention measures and treatment: clinical, social and emotional.

The main goals we would like to reach from Fundación Lucia with these tales are:

- 1.- Enlarge the efforts to avoid infections.
- 2.- That people infected and affected by HIV reach a high level of life quality in our society:
 - a) By making possible and supporting the communication process of infected and affected minors.
 - b) By improving knowledge of the HIV infection in order to permit the acceptance of infected and affected people without fear and rejection because of the lack of information, starting the outreach in really early ages.

With this second objective, we consider that our project would be able to respond to the concerns that we gathered from our participation in all the European Meetings that had taken place years ago. In those meetings, young people infected by VIH talked about how and when they would have liked to be told about their diagnosis. Their relatives or tutors, to protect them, took too much time to inform them, and some of them did not know how to do it in the right way. These young people would have preferred to know before about their real situation, and to have all the information that would have permitted them to better understand some things of their life. They would have preferred to be told about their diagnosis by some close relative, parents, grand-parents or educators although this is not easy because most of them have doubts when talking about some clinical or psychosocial aspects about HIV.

In support to our project, there is also the fact that in the communicative process, when there is the need of communicating bad news, or painful ones, with a huge emotional charge, this is projected from the emitter to the recipient in a straight and impacting way. The existence of some complementary material, supporting the communication, makes it easier, as it creates a third element in the talk that reduces the intensity of the message, lowering the emotional charge of the news.

In conclusion, we provide supporting material to promote the resilient process and to protect and strengthen the minor's right of information.

We believe that outreaching factual information and providing it in early ages will improve the acceptance and integration of infected and affected people with whom it is possible to share lots of things. There is no risk in living with them, so there is no need to avoid the contact with these people, to stigmatize or reject anybody. All these ideas need to be explained in earlier stages of people development, in order to assure they will grow up with these values.

There are 10 tales; there is a wide targeted age range and there are several aims; each tale has as main axis a topic and around this topic there are included concepts related to the HIV infection:

- 1.- Transmission pathways
- 2.- Treatment and therapeutic approach: clinical and pharmacological.
- 3.- Approach to social, and emotional needs of infected and affected people.
- 4.- Considerations about Human Rights and Children's Rights.

There are some considerations to be made when using this collection:

- 1) Treated topics are complex for children, so we recommend that an adult join them through its reading and comment its contents with them.
- 2) The context of all the tales is our country, Spain, where there is access to treatment. Here, infected people can have a good life quality but it is not like that everywhere. There are a lot of countries where being infected involves a certain short-term death, because of the lack of ARV treatments. However some of the tales can also be useful in these countries for emotional work, as the contents are wide and assorted.
- 3) Related with treatments, they are described and commented based on the available ones when the tales were written, but there were worse periods, with no treatments, and also there is the hope of their improvement.

4) The main goal of these tales to reduce the social stigma of the HIV infection and of people who suffer it, modifying it from the most possible factual point of view.

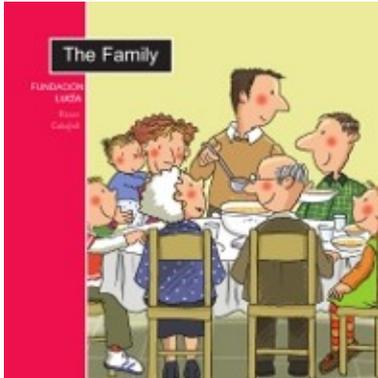
5) The whole collection is thought to work with children and to answer their questions when there is the need.

It supports adults when they must talk about the infection with children and for children, it is a basic tool of information and prevention.

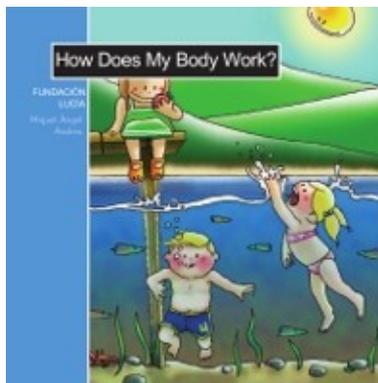
For affected children there are some tales that must be read before the diagnostic communication, tales n°: **2 – “How does my body work?”**, **4 – “Visiting the Hospital”**, **5 – “Trusting and sharing”**, **6 - “A normal day”**. The other ones are for treating concerns that children wonder once they know about their situation.

6) There are exercises with each tale, to promote reflection and to help the comprehension.

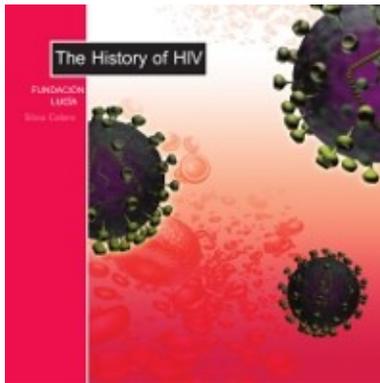
INDIVIDUAL GOAL OF EACH TALE:



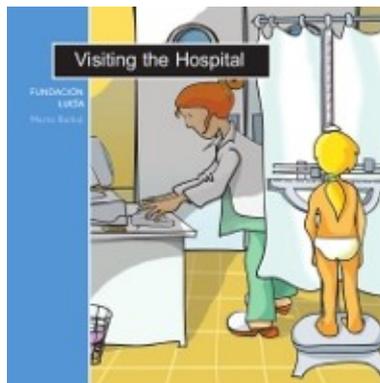
- 1) **“The family”**: we all have a family. Our family history can be a happy one, but sometimes there are some sadder periods, and this is a common point in every family, it is no exclusive of living with HIV.



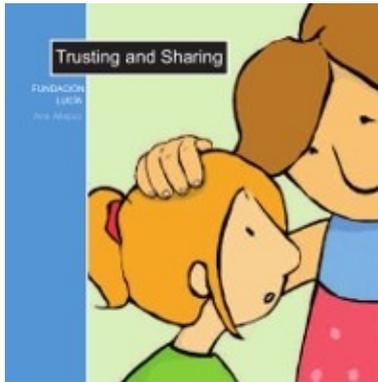
- 2) **“How does my body work?”**: there are some anatomy and physiology concepts, explained in a simple way, that are necessary to better understand the self-caring when there is an HIV infection.



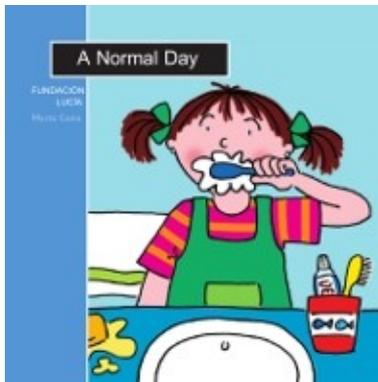
- 3) **“The History of HIV”**: here it is told the beginning of HIV, its discovery, its mechanisms and how to prevent its infection.



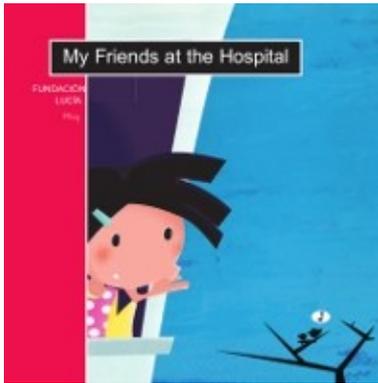
- 4) **“Visiting the hospital”**: to be well caring of one's health there are some necessary checks at the paediatrician. The difference with infected children is that they have to do them more often.



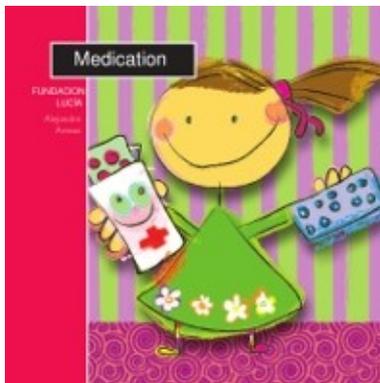
- 5) **“Trusting and sharing”**: social rejection has led infected people to protect their intimacy, to protect themselves from the discrimination and from the abuse; we must take into account that this behaviour, in extreme cases, will involve social isolation and loneliness. We all need to be connected to people, but we have to choose with who we want to be.



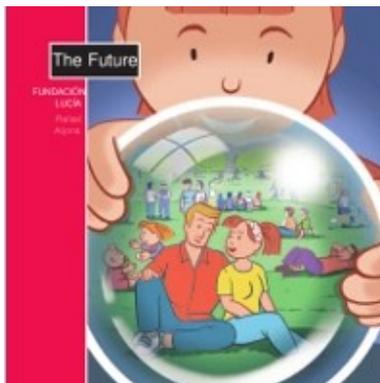
- 6) **”A normal day”**: daily life for children who take medication is somehow different. However, given that they are children, we have to attend to several other needs that have to take up the main part of their day.



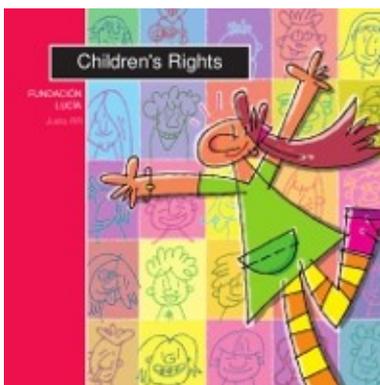
- 7) **“My friends at the hospital”**: there is a wide range of life experiences related to HIV and we wanted to show some other different from the one of Lucia. It is fair to say that this is not the Lucia who gave the name to our foundation.



- 8) **“Medication”**: this one explains, in an adapted way, a complex topic as the pharmacological mechanisms of the medication that avoid the infection to go ahead, and why it is necessary to use drugs in order to fight the HIV.



- 9) **“The future”**: The hope in an existing future is the connection with life. As infected people, children can make plans for the future and here we try to give an answer to their wonders.



- 10) **“Children's Rights”**: some concerns about children, adolescents, and their rights.

In the back cover of the books there are these instructions. They are attached to a removable sheet that educators may use as a support to make the choice of which book they should use in each situation, when working with the children they are in charge of.

TARGET POPULATION

1. Paediatricians, educators, families, child carers
2. 7 to 13 years old child population infected and affected by HIV/AIDS.
3. 7 to 13 years old general child population and pre-adolescents.



CLASSIFICATION OF THE TALES

Information has to be given progressively. The communication of the diagnosis is a complex and dynamic process and an excess of information could be harmful for children if it is used in a bad way, and can provoke rejection from the social environment (school, neighbourhood). That is why these collection is divided into two groups of tales, one of them containing explicit information about HIV, and the other one just dealing with related topics, but without having direct references to the infection. These tales are an adapted tool that can be used in all the different stages of the development of children, ranging from their childhood to their preadolescence.

In this way, adults can work with younger children that do not know their diagnosis and have the possibility to choose the moment when they want to reveal it. Then, there are the books for older children who already know about their situation and with whom it is possible to talk outright about HIV.

About prevention, when used with general child population in schools, workshops, summer camps, etc. there is also this possibility of adapting contents depending on the age range and the treated topic.

The colour of the cover frame distinguishes the books from each group.

Classification of the tales: Y (younger children) O (older children)

- | | |
|-------------------------------|---|
| 1. My family | O |
| 2. How does my body work? | Y |
| 3. The History of HIV | O |
| 4. Visiting the hospital | Y |
| 5. Trusting and sharing | Y |
| 6. A normal day | Y |
| 7. My friends at the hospital | O |
| 8. Medication | O |
| 9. The future | O |
| 10. Children's rights | O |

EVALUATION

There has been an evaluation process of this material in all the centres where the books were distributed and based on the predicted objectives:

- 1) As a tool in the communication process in families living with HIV.
- 2) As a training tool and helping the HIV preventives activities in child population.
- 3) As an integrative tool, collaborating for the acceptance of people infected and affected by HIV.

They obtained an optimal acceptance of the marked standards:

Results of the validation of the material in workshops and activities with minors

| | |
|---|--------|
| Children's acceptance of the activity | 81,25% |
| Degree of satisfaction of the seminaries | 84% |
| Comprehension of the Lucia's tales by the children | 93,75% |
| Teachers value positively workshops using Lucia's Tales | 96,87% |

“Lucia's Tales” are available in the website of Foundation Lucia for Paediatric AIDS:

www.fundacionlucia.org

In the following languages:

- Spanish
- Catalan
- English
- French
- German
- Italian

You will find them in the website section “Lucia's Tales”. There you can **download them in a PDF file, print** them, and **use** them in your workshops with children.

Please, do not forget to do some reading comprehension of the stories. For scholar groups with proposals of some examples at the end of each book.

DALITSO'S TALE



Our collaboration with NGO working in Africa made us think about the need to adapt Lucia's tales to a new format. This one should needed to be showing the reality existing in Africa to be more useful to professionals in the HIV caring area and educators of this continent.

The books were transformed into a workshop poster where all the essential was shown: transmission paths, prevention, rights, respect for intimacy and confidentiality, and caring of infected/affected minors and families.

Our protagonist changed her name, to better match with and be closer to children in Africa. In this poster, the girl who talks with us about the HIV infection in the paediatric age is called Dalitso.



This material can also be seen and downloaded in our website, and was given to the NGO Active Africa for their work in Kenya and Malawi.

LUCIA'S TALES

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DESIGN – REVIEW – EDITION

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