



AGIHAS 25

at the forefront





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Copywriter, editor: Guna Zvirbule

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These 25 years have been our way. Sometimes - straight and smooth, sometimes - winding and unsafe. We have made many mistakes and learned plenty of lessons. We have had times of success and times of failure. We have been defeated and we have won, experiencing unexpected ups and painful downs. But most importantly, this way has been and still is ours and ours alone. Most importantly we have not strayed from it, even when we lacked patience, strength and faith in ourselves. Even when it has not been easy to walk on and we didn't feel paved and smooth ground under our feet.

Thank you for being with us during these 25-years. Thank you for supporting, encouraging, inspiring and trusting us. Thank you for your promise to be with us further on. Thank you for more, much more than this. Thanks to you, these 25 years have been possible. Thanks to you, they have been worthwhile and meaningful. Let's keep going - towards our next 25 years!



● Courage, which grew out of fear

I begin, perhaps, with a metaphorical view, but on this occasion for me, it seems appropriate. Age 25 is a borderline, when our impetuous youth is behind us, and a more conscientious vision of life takes hold. This is a time when both the desire and the ability to look into oneself appear, and we start to recognize that the problem is not in others. It is difficult, to honestly examine oneself. Of course, we want to justify ourselves. Always, whenever we notice hatred, aggression or self-righteousness; or fear of rejection, or an inadequate assessment. Minor egotistic fear that may give root to the huge collective fear.

It's possible, that fear was specifically the impetus why 25 years ago various generations of people came together as one to face a huge challenge - overcoming denial and accepting themselves, recognizing their reality and their status; to come out onto the harsh stage of openness and vulnerability and say: "Here, in Latvia, we are not strangers".

AGIHAS - these are the lives of real people, unique experiences, immediate stories that belong to Latvia and are necessary for all of us. AGIHAS - this is an opportunity for the public to get to know themselves, to learn to overcome their arrogance and to truly accept those that are different. AGIHAS - is also the incessantly writhing question: how many of us are there, who are we and why are we even here?

In Latvia we have social groups which are as if invisible, and problems which are not talked about. Opening our eyes and seeing reality, is however too embarrassing and painful. But there are no other options. Do we all together want to become a more humane, inclusive and tolerant society. This is what we've dedicated our first 25 years to. And we want to spend the next 25 - inviting every person to dive deeper in his or her personality, and instead of looking to change and judge others to first think "what can I do to become a better and brighter person myself?"

Andris Veikēnieks,
AGIHAS,
Chair of the Board





● Personalities

Throughout the whole of its 25 years of existence, the organization's development and growth has been fostered and boosted by strong personalities. First and foremost - health care professionals.

Prof. Ludmila Vīksna, who, thanks to her exceptional professionalism, already in the very beginning substantially contributed to the standard of AGIHAS performance. Both medically and socially – promoting the access to medicines and the capability of AGIHAS to enshrine in law and government policy the right to disability pensions for HIV+ people, as well as providing administrative and technical support for the organization's activities.

Dr. Māra Spredze, who not only professionally, but also on an interpersonal level respected and guaranteed the anonymity of AGIHAS members, being a person of trust and supporting beyond the scope of a doctor's usual role and working hours. Back then, in the early nineties, it was extremely important for two reasons - first, because patients and doctors had so little experience how to deal with the HIV infection; and second – society regarded the HIV diagnosis as a 'public death sentence'.

The current leadership of the *Infectology Centre of Latvia* - Prof. Baiba Rozentāle and Dr. Velga Kūse, the heads of both the 2nd outpatient and the 6th inpatient wards - Dr. med. Inga Ažiņa, Assoc. Prof. Gunta Stūre, medical nurse Iveta Magone – people, without whose input, professional and personal interest and commitment, the later AGIHAS projects would not have come to fruition.

And of course, the first leader of AGIHAS - Ivars Kokars, who led the organization for twenty years. He did so intelligently, wisely, responsibly and diplomatically, laying a strong foundation for the work ethics of AGIHAS, thanks to which, the organization has been able to achieve respect and influence. It is trusted by all its cooperating partners - government institutions, health care professionals and businesses.



● A wise mediator, professional assistant

HIV / AIDS - the terror of the twentieth century, but at the moment - a chronic, controllable contagious disease. However, at the time when others were fearful, AGIHAS acted - both emotionally and rationally.

Any chronic, controlled contagious (including, HIV) case should have two parties - highly qualified doctors and patients' adherence. Adherence in the case of HIV is not only particularly important, but also quite difficult to achieve; because this disease, both from the patients and society's part is wrapped in a particular aura of denial and stigmatization. Therefore, it is very important for the medical personnel to have a reliable and responsible assistant, who, poetically speaking, like a wise mediator, places the patients hands into the doctor's palm, thus contributing to both sides cooperation on the way to the total and successful disease control.

AGIHAS fulfills this role intelligently and patiently, by not only recently creating the "Adherence Office", but systematically and conscientiously caring for patients', for their improved life quality, and, of course, to change society's attitudes and understanding. At the same time seeing the big picture, and well understanding that the infection not only spreads, but is also born, grows up and gets older. Such a professional partner is worth their weight in gold. And for this, I extend to AGIHAS my heartfelt thanks.

Prof. Baiba Rozentāle,
doctor in-chief,
Infectology Centre of Latvia,
Riga East Clinical University Hospital





● Goodwill

Administrative positions have never been paid at AGIHAS. Since its establishment the organizational burden has always been shouldered by the AGIHAS leadership, who has done this work on a voluntary basis. This includes: setting up the contacts with partners and decision makers, successful fund raising and ensuring fiscal control. The lack of 'paid administrative staff' has not become an obstacle for AGIHAS's professional growth and development, as well as its ability to pursue new areas and forms of activities. The organization has achieved its influence and results not by the quantity of its members and deeds, but by the scope and quality of its accomplishments, including responsibility, aspiration and clarity of goals and their merit.

● A capacity for growth

With the years, the level of engagement and activities of AGIHAS members has grown both internally and externally. The originally relatively 'narrow' scope of activities has now reached the national level of the advocacy of HIV/AIDS patients' rights and interests, participation in the health care policy shaping and the associated decision making processes, thus manifesting AGIHAS social and civic maturity, capacity for international cooperation, enlargement of competence and the ability to grasp and see the 'bigger picture', as well as the awareness of ever new areas of strength and directions of operation.

● Traditions

The basis of AGIHAS's stability and sustainability is its traditions - faithfully and meaningfully developed and cherished year by year, and also created anew by plenty of inspiration. The main concept being that they are



● Proof of public influence and power

AGIHAS is one of those organizations that have demonstrated the influence and power of the public, as several initiatives that it has launched and brought to fruition, are today included in the law or policy planning documents, and have become state supported activities. AGIHAS is an excellent example of the link between policy makers and society, an example of how to explain and discover what society actually feels and needs.

Thanks to its skills of diplomacy, tolerance and desire to cooperate and engage, it has achieved very much. AGIHAS people deserve both – gratitude for timely and appropriately expressed criticism as well as recognition and praise. The great American basketballer Michael Jordan's words well characterize the AGIHAS team: "The world makes way for people who know where they're going".

Jana Feldmane,
Head of the Environmental
Health Department,
Ministry of Health of the Republic of Latvia

● Seeing further and wider

AGIHAS always sees further and wider. This was certainly the case when the organization not only realized this unmet need, but also took practical care of children born to HIV positive mothers; thus contributing not only to the disease prevention of these babies, but also promoting their mother's adherence to therapy. The significance of the AGIHAS initiative "Child Isn't Guilty" can't be overestimated - I do not know another example where a non-governmental organization's project has in such a short time become a national program, supported by government.

Signe Vēliņa,
Market Access Manager,
Johnson & Johnson, Latvia





respected and maintained because of their essence, not out of habit or a sense of duty.

- The AIDS Candlelight Memorial is marked every year on the third Sunday in May (since 2003) - by creating a living floral emblem in the shape of the HIV/AIDS red ribbon at the Infectology Centre of Latvia, and the laying of flowers and candles at the 'victims' of HIV/AIDS memorial at the intersection of Marijas and Satekles streets in the Riga city centre - the small memorial with the names of some of those died of HIV/AIDS engraved in the cobblestones.
- The marking of World AIDS Day on December 1st - until (and including) 2015 with various events, and since 2016 with a Charity concert and Award "Glāsts" (shaped in the form of a 'caress' and given for noteworthy contribution to the reduction of HIV infection in Latvia) ceremony.
- Monthly informal member meetings - 'a friendly shoulder' as support, sincere conversations, jokes, humor and advice based on personal experience, which not only boosts resilience and eases the disease control, but also reduces social isolation and the emotional burden created by the infection.
- Annual summer camps – 3 - 4 day motivational events for active AGIHAS members and people who have recently been infected with HIV. Building up the strength of self-awareness and self-esteem, learning to ask for and give mutual support and adding to life-power needed for the life-long disease control.



● It's hard job, to be the one that provides consolation...

Being HIV + and being a woman is particularly difficult - accepting the diagnosis, maintaining peace of mind, taking care of your loved ones, and especially children. At such a moment, it's extremely important to find someone who can help. Someone who simply listens - without reproachment, without undue prying, without unnecessary questions...

It's a hard job - being the one that refreshes; when you are tormented by a thirst for help. But someone has to be the first - the first to take the initial step, the first to have the courage to start something new. AGIHAS wants to do this, and is capable. They took the first step in the implementation of the project "Child Isn't Guilty", which provided HIV + mothers' babies with milk formula. They were the first to set up a support group for HIV + women.

Assoc. prof. Gunta Stūre,
Head of the 6th in-patient ward,
Infectology Centre of Latvia,
Riga East Clinical University Hospital

● Commitment and openness to innovation

AGIHAS – it's always a sense of commitment, a fighting spirit, and openness to change. Evidence for this is also the creation and operation of the HIV "Adherence office" - an innovative and important project for patients.

Andris Gailītis,
Customer Service Manager,
Johnson & Johnson, Latvia





● United in shared misfortune and pain. Strong in the will to survive

In the beginning of the nineties AGIHAS was more than just 'simply' providing support to people who became aware of their diagnosis - which most people at that time believed to be fatal. AGIHAS helped the first Latvian HIV patients stand strong on this side of the chasm of hopelessness - uniting them in joint misfortune and pain, and a very strong will to live...Invaluable role was played then by Māra Spredze, the Head of 2nd outpatient ward - doctor, mentor and person of trust at the same time.

In my memories the beginnings of AGIHAS are very much related with Ivars Kokars, founder of this NGO. Ivars came to me in 2008, when I started to head the 2nd outpatient ward - due to the financial crisis, difficult problems emerged, limiting the access to antiretroviral therapy in Latvia. We understood that in time of such hardships the NGO and doctors had to be united. And then followed 2010, when antiretroviral medications were included in the reimbursement list, but with criteria that restricted the access to them. Again we had something to fight for...

I mention concrete names, because it is specific people who, utilising their strengths and abilities, play a vital role in leading patient organisations. I can say the same for the current leadership of AGIHAS, thanks to whom, the organisation implements an up to date and diplomatic style of co-operation, that culminates in unheard of and important improvements in HIV patients' treatment and care - expanded access to treatment, the provision of infant milk formula to babies of HIV+ mothers etc.

Dr. Med. Inga Ažiņa,
Head of the 2nd outpatient ward,
Infectology Centre of Latvia,
Riga East Clinical University Hospital





25 years in facts and numbers

- AGIHAS: **35** members
- more than **80** completed projects
- participated in **150** international conferences

1993

- AGIHAS, *Support Group for People Living with HIV/AIDS* is founded - the first HIV/AIDS NGO in Latvia.
- Within the framework of the World Health Organization's conference "Investments in Health Prevention" there is also a meeting of Health and Finance Ministers about HIV infection and preventative measures for AIDS in Central and Eastern Europe, at the conclusion of which they came up with the idea of creating memorials for the victims of HIV/AIDS, where such memorials did not yet exist. With the participation of AGIHAS, Latvia also got one - at the corner of Marijas and Satekles streets.

1994

- Thanks to AGIHAS, Latvia is the first post-Soviet country in which HIV+ people start to receive the disability pension.

1998

- AGIHAS publishes its first informative brochure "A better quality of life for HIV+ people". This is the first in a series, with 26 others to follow by 2013.

2002

- AGIHAS is one of the founders of *DIA+LOGS* – Support Centre for Those Affected by HIV/AIDS.



● Professional wind catchers

Oscar Wilde said that a person can not affect the direction of the wind, but can adjust the sails so that the boat reaches its goal. I think this lesson applies very precisely to AGIHAS - because thanks to their accurately adjusted 'sail', many HIV/AIDS issues in Latvian society are developing in the proper direction of understanding.

Prof. Ludmila Vīksna,
Head of Infectology and
Dermatology Department,
Rīga Stradiņš University

● Pioneers in the process of change

AGIHAS activists were the first in 1993 to focus on changing society's attitudes towards HIV patients, and the associated prejudices and stigma. But even more significant than this investment, in my opinion, is the NGO's cooperation with medical personnel, to develop mutual understanding and trust in the treatment process.

Without trust, support, understanding and goodwill between society and healthcare professionals, it is not possible to achieve good HIV treatment results and disease control, as well as reduce the spread of infection. AGIHAS were the first to start this process of change.

Ilze Aizsilniece,
General practitioner





2003

- AGIHAS begins a tradition - marking AIDS *Candlelight Memorial Day*, which over time gains not only wider ambitions and publicity, but also a definite 'format'. One integral part of this is the creation of a living floral tribute in the territory of the *Infectology Centre of Latvia*, in the shape and colour of the HIV/AIDS ribbon.

2005

- AGIHAS is granted charitable tax-free status.
- AGIHAS joins the ECUO (*East Europe & Central Asia Union of People Living with HIV*).

2006

- AGIHAS joins the newly formed coalition 'HIV.LV'.

2008

- A new initiative for Latvia - the first AGIHAS Summer camp for HIV+ people takes place, and is organized every summer. Winter camps occur less regularly.

2011

- Another new initiative for Latvia - AGIHAS starts 'peer to peer' consultations.

2013

- AGIHAS publishes a special booklet - a collection of emotional life stories of HIV+ people 'Life after the turning point' in Latvian and Russian.



● The trailblazers

AGIHAS were the first who understood that HIV+ people had to unite, in order to attain specific goals that would allow them to feel safe, receive support and assistance and reduce society's fear and misunderstanding. AGIHAS was also the first to see the need for the engagement of a broader cross section of society, as a result of which DIA+LOGS was formed. And in 2002 AGIHAS was the first signature on the foundation protocol of DIA+LOGS – the support organization for people affected by HIV.

Ruta Kaupe,
"DIA+LOGS", Support Centre for Those
Affected by HIV/AIDS,
Chair of the Board

● A strong willed and professional team

AGIHAS is an authoritative and successful organization, who's accomplishments and experience are significant not only for Latvia, but the entire Eastern Europe and Central Asia region. AGIHAS - it is a strong willed, professional and selfless team which always meets its set goals, and during its 25 years of activity has grown from a number one advocate of HIV/AIDS patients' rights and interests to a strong originator of crucially needed legislative and therapy paradigm changes.

Inna Gavrilova,
Director of communications at ECUO
(*East Europe & Central Asia Union of
People living with HIV*)





2015

- Thanks to the financial support of *Latvian State Forestry* and in cooperation with the charitable organization "Ziedot.lv", the *Riga Maternity Hospital* and the *Infectology Centre of Latvia*, AGIHAS begins the "Child Isn't Guilty" initiative in Riga. In the framework of this project practical assistance is provided to babies born from HIV+ mothers or mothers with AIDS.
- AGIHAS (in cooperation with "DIA+LOGS" and the "HIV.LV" alliance) engages in the *ViiV Healthcare* supported project "Latvian buddies and support for HIV+ people" (the project is extended and completed in 2016) in which volunteers are trained and prepared medically, socially and psychologically to be able to provide support and assistance to people infected with HIV.



● Ministers of love

AGIHAS were the first to dare with their example to come into the light, helping many to understand and accept that we need all people.

I remember the time - the nineties, when post-Soviet society viewed life in the "one truth" format. AGIHAS's work has helped our society to take an important step from the Old Testament law - "Thou shalt not ..." to the New Testament - "He loves us all".

Dins Šmits,
JSC "Repharm",
President of the Board of
Directors

● With persistence and heartfelt wisdom

My meeting with AGIHAS was sudden, but not random. Since I worked for many years in Estonia, I knew that for a long time the Estonian government is supporting babies who were born of HIV positive mothers. They are provided with milk formula for all of the first year of their lives, because unfortunately they should avoid their mother's milk due to the infection risk. AGIHAS were the first to start the provision of this type of support in Latvia. Thanks to AGIHAS's persistence and heartfelt wisdom, this project, upon receipt of donors support, went on for two years, and because of their persistence and faith, as of 2017 transformed into a government initiative.

Irēna Putniņa,
German Products Baltics,
Managing director





2016

- Thanks to the repeated support of *Latvian State Forestry* and in cooperation with "Ziedot.lv", *Infectology Centre of Latvia*, *Riga Maternity Hospital* and maternity wards in hospitals in Tukums, Kuldīga, Liepāja, Ventspils, Valmiera and Jēkabpils, AGIHAS continues the "Child Isn't Guilty" initiative at a national level.
- AGIHAS (in cooperation with "Mosaic" and the "Baltic HIV Association") starts the *ViiV Healthcare* financed project "Coalition for Change" (the project was continued and completed in 2017), whose goals were to consolidate the Baltic Sea region NGO's, promote regional cooperation, transfer good practices and represent the interests of patients in all involved countries.
- AGIHAS implements the project "Know, don't guess" which carries out a survey of 300 HIV infected people in Latvia and finds out their opinions and genuine needs to further their integration into society.
- AGIHAS joins the project "Women. Children. HIV" - the creation of an exhibition of three Baltic photographers' work, which includes 15 unique art photographs. The photographs were taken to lessen peoples' stereotypes and fears around HIV infection and stress the increase in the spread of the infection amongst the most vulnerable society groups - women and children.
- AGIHAS implements the program "I know! Do you?" within the framework of which the Latvian society is invited by various celebrities (by means of a video clip) to find out their HIV status.
- Working with AGIHAS, two attractive and popular TV personalities, Lelde and Aivis Ceriņi, take on the role of HIV Ambassadors in Latvia.
- On the 1st of December, World AIDS Day, the first HIV/AIDS charity concert "The Latvian story of HIV/AIDS over the past 30 years" takes place at the Anglican Church in Riga with the participation of popular musicians and singers.



● The ability to evolve and transcend boundaries

AGIHAS is one of the first patient organizations through which *GSK Latvia* began collaborating in the early nineties. Over the years, AGIHAS has proven to be an organization that not only develops and grows far beyond its original limits, but also looks to the future. This ability - seeing one step further - is evidenced by projects that have grown from a non-governmental sector initiative to a nationwide program - both "Child Isn't Guilty", which ensures the availability of mother's milk substitutes to HIV-infected mothers, and the Adherence office at the *Infectology Centre of Latvia*. AGIHAS, with the support of *Viiv Healthcare*, has done a significant job in shaping the "Coalition for Change", uniting HIV/AIDS NGO's working in the Baltic Sea Region. Cooperation with AGIHAS has personally brought me not only knowledge of HIV, empathy for people living with HIV and experience in implementing joint projects, but also new friends!

Sabīne Puķe,
GSK Latvia Communications and
Patient Advocacy Manager

● First patient advocates

AGIHAS is not only the first HIV/AIDS patient advocacy group in Latvia, but also one of the first non-governmental organizations, that began to actively engage in defending the interests of patients. During these 25 years AGIHAS has developed and matured as an organization, and it can safely be considered one of the most prominent and most recognizable advocates of patients' rights not only in Latvia, but also in the Baltics. AGIHAS's contribution to public health in Latvia is invaluable.

Kaspars Arkliņš,
Gilead Sciences Estonia, Latvia,
Lithuania





- AGIHAS creates the Award 'Glāsts' (for significant contribution to the reduction of the spread of HIV). The award is made by sculptor Olga Šilova and is presented during the charity concert mentioned above.

2017

- AGIHAS creates the first special support group for women, which begins to provide the 'peer to peer' consultations.
- The first in a series of "AGIHAS Library" booklets is published, entitled "Woman and HIV. Life after diagnosis".
- The first informative and educational video discussion "Women for women. HIV" is produced.
- AGIHAS, in cooperation with *Infectology Centre of Latvia* starts a project "Adherence office" whose goal is to assist patients in their disease management and increase their understanding about the importance of adherence in successful treatment and control of viral load.
- On the 1st of December, World AIDS Day, the second HIV/AIDS Charity concert "This fragile line between plus and minus" takes place at the Anglican Church in Riga, again with the participation of popular musicians and singers. For the second time also the Award "Glāsts" is presented.



● In lieu of an epilogue

To be perfectly honest, I too was not an exception. Like many of us (I'm not afraid to admit), I walked around with altogether rather dark prejudices and cautionary 'blinkers' over my eyes for a certain period of time - looking and perceiving everything to do with HIV through a relatively limited and bigoted filter. For me as well the 'background music' quietly played the old song of good and bad diagnoses, of right and wrong patients. All this in spite of the fact that I've had a certain professional contact with this sphere.

And then three years ago I developed a closer co-operation with AGIHAS, and this experience essentially 'corrected' my view and assessment of people and the world, to not even mention the unique professional satisfaction that I gained.

What is my understanding today?

It is not self evident that we, HIV negative people, do not have a diagnosis of HIV. And that this is by no means due to ourselves, or our actions. In truth, no one is safe and protected. We've simply been very fortunate.

That we don't have a clue as to what HIV+ people have gone and are going through. That's why we have no right to judge, 'classify' or somehow feel superior or proud of our HIV- status.

That AGIHAS does endlessly blessed and socially responsible work, to not only help those who have received the harsh judgement of HIV, but also for us, that part of society that is HIV negative, to become more knowledgeable and informed, to protect ourselves and to realise that the boundary between this side and that side of HIV is truly fragile and sometimes unnoticeable.

GunaZvirbule,
AGIHAS Communications Consultant







- It is a heartfelt pleasure to hear that there are such enterprising, brave and compassionate people in Latvia, who believe in the idea of a better world, although they operate in a sector that does not deliver results easily and quickly.

Lelde Ceriņa,
HIV ambassador in Latvia

- AGIHAS - this is a great reminder that you must take care of, and think about your own health, and your partner's health every day. If you notice AGIHAS, remember it!

Aivis Ceriņš,
HIV ambassador in Latvia