PUBLIC ASSOCIATION OF PARENTS OF CHILDREN WITH AUTISM "HAND IN HAND", KYRGYZSTAN.



Our History

Public Association of parents of children with autism, "Hand in Hand" was organized in June 2012 by a group of parents. The creation of the Association was caused by the lack of public awareness about Autism.

The first classes were taught by Chihiro Tamura who used the TEACCH method. He worked with each child in a small room provided by APCD once a week during four months and clearly demonstrated that our children are teachable.

Joanna Major was providing the first workshops for parents at the Hope

Academy during two months. She helped many parents understand for the first time the behavior of their own children and taught first steps to work with them...

The first conference on Autism, which our parents attended, was held in Dushanbe, Tajikistan, under the auspices of CAAN (Central Asian Autism Network) where first acquaintances and contacts were established

We received our first moral and material support from the Public Foundation «Kelechek HP»





Our mission:

• To create a decent future for autistic children in Kyrgyzstan

Our objectives:

- Introduce the problems of child autism to parents and professionals; teach them techniques and methods of correctional treatment and education.
- Encourage broad and correct coverage of the problems of autism in print and electronic media, creating a tolerant and favorable public opinion on children with autism.
- Protect and promote the rights and interests of children with autism at the local level and at the level of legislation in terms of the access to education, health care and social integration.

Our activities:

The Center of support for children with autism was opened in September 2012, where the parents of 20 children are receiving advice of experts and exchange information, personal experiences, and children attend individual classes have an opportunity to spend time outside their home in the community of their peers. The following foreign experts consult at the Center: USA - William Edwards, Joanna Major, Japan - Hirata Setsuo, Chihiro Tamura (They shared their knowledge and experience through a JICA project during 10 months). The main techniques used for testing, treatment and education of children: ABA therapy, TEACCH, PECS and ABLLS-R protocol, of which the latter was translated and implemented

as part of a project supported by Abilis Foundation. Thanks to the ABLLS-R protocol, we have the opportunity to test the levels of children, develop individual training programs and track their progress, which greatly improves the quality of correction.



The website <u>www.autism.kg</u> was opened, where every internet-user can find relevant information on autism issues, we have also opened a page on Facebook: <u>www.facebook.com/rukavruke</u>

From November 20 to 22, 2013, the first international conference on autism was held in Bishkek. Relevance and timeliness of the topic were confirmed by the number of active participants in the conference. During three days, more than 300 people participated in its work, including: teachers and students of Bishkek universities, pediatricians, neurologists, speech pathologists, speech therapists, parents, NGOs and representatives of public associations

In 2013, seminars for pediatricians were held in Bishkek, and a meeting on early diagnosis of autism was organized with leading child psychiatrists at the Republican Center for Psychiatric Health.

As part of the Autism Awareness Month, the following events were held in April 2014: competition of movies about autism, an exhibition of drawings and crafts made by autistic children, round tables, press conferences with the participation of representatives of government agencies, "Open your eyes for Autism" campaign in social networks.



According to a joint project of Clemson University, USA, and AUCA supported by Soros Foundation in Kyrgyzstan, there was launched a course for psychology students - "Introduction to autism and applied behavioral analysis" at the AUCA. The practical part of this course takes place continuously on the basis of our Center of support for autistic children. Since August 2014, instead of parents-volunteers, graduates and students of the AUCA work at the Center.

Since September 2014, according to the contract with the Department of Education in Bishkek, the first ABA-class was opened at the specialized school # 34 for non-verbal children with moderate and severe degrees of autism. Children from the Centre, who had been trained and had reached the school age, for the first time, had the opportunity to receive education in a public school.

Before starting the classes at school, in the framework of the project "Establishment of a pilot ABA-class for children with autism at the specialized school #34 in Bishkek", UNICEF had allocated co-financing to conduct seminars and workshops to train a team of tutors, teachers, educators and psychologists of the ABA class at school #34, and to organize the arrival of two experts from the United States. Thanks to the workshops, teachers of the specialized school #34 could successfully use the basics of the Applied Behavioral Analysis in work not only with children with autism, but also in teaching children with other developmental disorders.

On the basis of specialized school #34, together with public foundation "Hear by the Heart", there was organized a computer class for children with autism, where during the entire academic year of 2014-2015, children with autism, their parents and teachers of the specialized school #34 are taught the basics of computer skills.





On September 4-6, 2014, representatives of Autism Speaks, the largest autism organization in the world, visited our Association. Vice president of Autism Speaks Andy Shih and coordinator for the CIS countries Amy Daniels arrived to assess the situation and determine priorities of cooperation. During three days, there were meetings with the Deputy Prime Minister of the Kyrgyz Republic Sarieva E.K., representatives of the donor community and key stakeholders. Andy and Amy also visited the Resource Center of PA "Hand in Hand" where they met and discussed cooperation with the Soros Foundation Kyrgyzstan, ICCO Cooperation, UNICEF, Kelechek HP, Eurasia Foundation of Central Asia, the NGO "Institute of Childhood", "Promotion of alternatives." They also made presentations at the American University for students and teachers of AUCA, KRSU, Arabaev KSU, KNU, Kyrgyz State Medical Academy; in the office of UNICEF, they made a presentation for representatives of the Ministry of Health, in school #34 - for parents-members of the PA "Hand in Hand".



At the invitation of the PA "Hand in Hand", from September 22 to 25, 2014, Dr. Robert G. Bakendorf with his team of experts visited Kyrgyzstan. Dr. R. Bakendorf is a clinical assistant professor of pediatrics at Oregon Health and Science University, President of the Oregon Association of Speech and Hearing, author of several books on language development of children with ASD, has twenty-three experience in private practice, has lectured in many universities of the country and abroad. Lectures of his team were held in Arabaev Kyrgyz State University and specialized school 334 for professionals and parents on the topic: "Autism spectrum disorders. The current state of affairs in the diagnosis and early intervention. Assessment of communication and language skills of children with autism. Examples of work with children with autism. Special education in the United States. Principles and Practice. Multidisciplinary approach and inclusion in the classroom. "



We are working on the project "Autism. Routes of aid" during the third month. This project was commissioned by the Ministry for Social Development of the Kyrgyz Republic. The project objective is to train teachers of special schools to work with children with autism during individual classes at home, in order to prepare those children for school. The project involves 8 teachers, 16 children with autism between the age of 7 to 11 years old, who had no access to education previously. During December, 2014, 8 teachers and 16 parents attended a 40-hour course on the basics of Applied Behavior Analysis. Parents and teachers are willing to work in a team.



In 2013, our organization joined the «Janyryk» network, in which there are 27 daycare centers throughout Kyrgyzstan, working with children with special needs.

Within a three-year project "Parents are leaders in building an inclusive society" with the financial support of ICCO Cooperation, PA "Hand in Hand" began to conduct regional workshops on early intervention and the rights of children with disabilities for specialists, representatives of local authorities and parents around the country. On November 5-6, 2014, there was a national seminar on training of trainers to conduct regional workshops in November and December 2014 in Naryn, Talas, Issyk-Kul and Chui oblasts on "Autism. Identification of risk groups of children with autism spectrum disorders". The purpose of the workshop was to train health workers (pediatricians, neurologists, family doctors) and representatives of day care centers the skills of screening to identify children at risk of developing

autism symptoms. Meetings with key government representatives on the ground who are responsible for working with people with disabilities were held and cooperation agreements for three years were signed.







Situation on Autism in Kyrgyz Republic, 2015

According to the Ministry of Health of KR, child autism is encoded within the diagnostic category "General developmental disorders» F84 ICD-10. At the beginning of 2014, 71 children were registered under this category.

In reality, the number of children with autism is much

higher, but the lack of specialists in the regions, the low educational level of the population in terms of knowledge about child development does not allow seeing the real picture of the autism prevalence in the republic.

Therefore, the social significance of the problem is completely underestimated by the government and by the society. Parents of children with autism spectrum disorders every day face a lack of systems of early diagnosis, care, rehabilitation and educational services, not to mention the absence of specialized centers for treatment and integration in modern society.

Universities of the republic do not train specialists for the correction of autism; students, in the best case, learn about autism within a small theoretical course.

The list of priority issues requiring the involvement of the government:

The Ministry of Health should develop and organize trainings for pediatricians in the process of training in universities and at the workplace on the systems of early diagnosis of the disease and provide necessary advice for parents.

The Ministry of Education of KR should open resource classes for groups of children with autism of preschool and school age at public educational institutions

The Ministry for Social Development of KR should consider the issue of compensation for home labor for those caring for children with autism

Ministry of Culture and Information of the Kyrgyz Republic should take an active part in the formation of tolerant and favorable public opinion about children with autisms through the state media.

Our Partners:

"Soros-Kyrgyzstan" Foundation; The Swiss Embassy in Kyrgyzstan; UNICEF; Japan International Cooperation Agency (JICA); The Ministry for Social Development of the Kyrgyz Republic; Autism Speaks, USA; The Global Fund for Children, USA; Clemson University, South Carolina, USA; American University of Central Asia (AUCA);

"The initiative of parents of children with autism "IRODA", Tajikistan; Autistic Children Support Foundation "Ashik Elem", Kazakhstan

OUR BANK DETAILS:

HOW YOU CAN HELP US:

- -BECOME A VOLUNTEER AT THE CENTER;
- Spend time with children with autism to give their parents
- A PERIOD OF REST;
- Assist in the preparation of educational materials for children.

PROVIDE ALL POSSIBLE FINANCIAL SUPPORT FOR:

- PURCHASING LEARNING AND PLAYTIME MATERIALS;
- RAISING AUTISM AWARENESS;
- INVITING INTERNATIONAL EXPERTS;
- TRANSLATING AND PUBLISHING LITERATURE ON AUTISM.

BANK

Bank: Chui prospect 245, Bishkek "Demir Kyrgyz International Bank – Main office» BIC: 118005 Account: KGS 1180000040909958 USD 1180000040910059