

“NoRo - Frambu, partnership for future” Project



RARE People and RARE Diseases

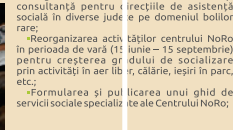
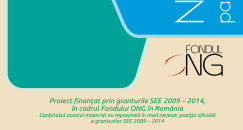
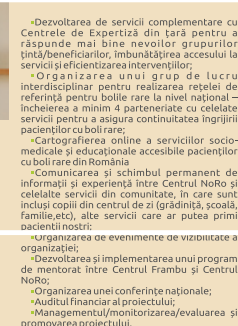
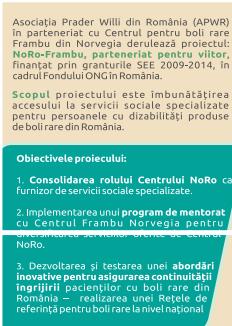
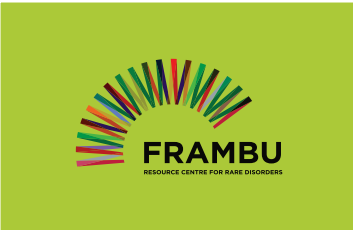
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NoRo – The story of a project



It's interesting to
tell the story of
a project that is
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nected to your
life project...

»page 4

NoRo – Frambu, partnership for future



Frambu has since
2009 the pleas-
ure of being a
partner with the
Romanian Prader
Willi Association...

»page 7

The Noro – Frambu mentoring program



The Romanian
Prader Willi
Association in
partnership with
the Frambu
Center for Rare
Diseases Norway
runs the project...

»page 16



www.eeagrants.org
www.norwaygrants.org



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a granturilor SEE 2009 – 2014*

NoRo – The story of a project

It's interesting to tell the story of a project that is very close connected to your life project... It is certain that our approach to others is more because of sharing the same thoughts and less about the way of living. We made friends not because they corresponded to a mental standard, but because they responded positively to a set of questions considered relevant to follow up a friendship. We did not even ask if they want to be our friends. We talked with them, we met, we shared the pain and joy, and so we tied our lives together. It was the same when we got to the conclusion that we could really do this, here with this center in Zalau, with the support of the Norwegian partners. Not because of some theoretical principles, not because someone or some institution has declared their support, but because this project created the same enthusiasm and belief in us and in partners. To believe in something does not mean you always are convinced by an amount of information, and sometimes I'd say that we even ignore part of the information to keep the dream alive...



Only if you follow your dream, you can reach it! It is a very interesting feeling to analyze how it happened and which facts concurred to the achievements you had in your life. As a person that never believed in having any kind of “leadership” skills, I think that now I am doing a pretty good job for the team that we have created in this project...

daughter's disease. It was my first trip by plane, my first contact with parents from all over the world facing the same problem as I do. It was not easy getting there. First it was a matter of money that I solved by a grant that I received through the German association for PWS. Then, when this problem was solved, I realized that I needed a visa from London, as we had no Embassy in our

But, let's start with the beginning! My daughter was diagnosed with Prader Willi Syndrome when she was almost 18 years old and we wanted that nobody else to face an unknown diagnose any more. As a result of the struggling to find information about the diagnose and to trace other families having member with this diagnose I created the Romanian Prader Willi Association – RPWA in May 2003.



In 2004 I've been attending my first international conference on Prader Willi Syndrome in New Zealand. It was a “life experience”, going at the end of the world to learn how to cope with my

country... and to get this visa, I needed a visa for England, too. Very complicated. I couldn't solve it without a good friend in Cambridge that helped me make this dream a reality.



The travel was not easy at all, as I went by car to Frankfurt, slept in the car and the next evening I took the plane for more than 30 hours. It was a real adventure... In New Zealand I met wonderful people that helped me think that I can really do the mission that I assumed to do for Romanian patients. I met Ragnhild Arnesen from the Prader Willi Association Norway, I met Pam Eisen the head of the International Prader-Willi Syndrome Organization (IPWSO) and found out that Pam's father was born in Felsőbánya-Baia Sprie (and I believed that it is in Hungary and then realized that it was in fact in Romania and very close to my town). I made friends and I was looking forward to meet them again at the next conference in Germany. Also, I had the opportunity to be in a workshop chaired by a special person, Christian Aashamar from Frambu – Resource Center for Rare Diseases, Norway. His presentation about Frambu kept my attention and remained as a dream for me because it seemed something impossible to be done in our reality. Nothing is happening in your life by mistake. But things began to develop rapidly. The German association decided not to host the following conference and in a “crazy” moment I decided that we can do it... and we did it in 2007! The conference included 388 participants from 38 countries, including Norway and we managed

to organize the arrangements to everybody's satisfaction! As from that moment we were more self-confident in our organizational capacity.

Also, in the same year we had established the Romanian National Alliance for Rare Diseases, we started to work for the National Plan for Rare Diseases and organized 2 conferences for rare diseases. I would say that it was the major step forward for our organization. In the same year I have been elected in the board of IPWSO and EURORDIS (The European Organization for Rare Diseases). In 2008, a call for proposals from Norway Grants was opened and I remembered the presentation about Frambu from New Zealand (sometimes you keep something in your heart and you don't even realize that it is still there) and I decided to try. I approached PWA Norway and asked for partnership for the seed money project and they agreed to prepare the project and to ask Frambu for partnership. Everything became possible because of two mothers, one from Norway and one from Romania that have met once in New Zealand... and when we lose our strength we are carried by hope... We have prepared a partnership agreement and a presentation of the project and met at Frambu in November 2008. At that time, all the information on Frambu's website

was in Norwegian language, so I based my application on the memories and my own dream. To be honest, I've been most impressed by the way Frambu approaches the entire family and community to improve the quality of life for the person affected by rare diseases. This is why the RPWA's vision was the “Norwegian reality” so to say...I don't know why and when we convinced them to be our partners (after the first day, I told to dr. Puiu that they will not accept to be our partners...), but, I assume there were some important elements: Ragnhild Arnesen from PWA Norway, the vision and my belief that we can do it in a very different reality as Romania. The director of Frambu saw this and signed the agreement the next day. We wrote the project and we won it. The implementation of the project was not easy as we wanted to achieve as much as possible for a better future for patients with rare diseases in Romania. But, the expertise of our partners was essential, the team and volunteers involved (Lisen, Tove, David, Kaja, Ragnhild, David Oziel, Christel, Anja, Nina, Rob, Romanian professionals and patients involved in the National Committee for Rare Diseases) were outstanding and the entire support from additional partners and friends helped us to do a good project.

The experience of our partners was essential in our project!

Project NoRo - “Norwegian - Romanian partnership for progress in rare diseases” has offered RPWA the opportunity to develop the services that we created through the Center for Information on Rare Genetic Diseases that we established in 2005. The eUniversity is developed as a service in the actual center for information and the Pilot Reference Center is a separate building created during the project implementation.

The construction of the center

That was another story with lots of challenges and efforts. First, we received the land through a partnership agreement from the Catholic Church “St. Family” Zalau. Then it was given back to the Local Council, who decided to give it to the RPWA (in accordance with the will of the church) to renovate and build the center for rare diseases, initially for 1 year, than 3 and finally for 10 years.

Through this project we built TRUST and UNDERSTANDING...We started with delays in the construction work due to the procurement methods and contestations, than we had floods, landslides, supplementary work for reinforcement of the land and many others... but, we overcome all these and succeeded in the end. Mainly because all the people involved constructor, architect, authorities, staff and volunteers, all of them transformed this project in their main goal and all wanting this project to be an example... I would say that our belief became their belief, and this is fantastic. This project is important for rare diseases patients as it is valuing the everyday experience of patients and families. One of our main purposes is to implement training activities for the entire family and for the professionals involved in diagnosis and management of the rare diseases. Also, it will offer an important support to all the patients, not only to those who have an effective treatment but also for those who have no treatment for the moment (through therapies, training, counseling and support group activities).Through this project we did not build only a “center” for rare diseases, but we built real partnership and trust among all the partners involved. The involvement of Frambu and PWA Norway is a model for the Romanian partners and this cooperation has influenced the support of the national authorities, too.

“If you fight for your dream, one day, the dream will fight for you, too...”

Dorica Dan, president of RPWA

NoRo – Frambu, partnership for future

Frambu has since 2009 the pleasure of being a partner with the Romanian Prader Willi Association in our work to improve the quality of life for people diagnosed with a rare disease. Funding from the EEA/ Norway Grants has enabled the two organizations to establish this partnership. We have succeeded in several projects and are now completing the project “NoRo- Frambu, partnership for future” during a 14 month period in 2015 – 2016. In this project we want to improve the access to specialized social services for people with disabilities caused by rare diseases in Romania.



The project was launched with a press conference in March attended by representatives from the collaborators in Romania and Frambu was represented by the director attending by video conference. Frambu stressed the importance of special services for people diagnosed with rare diseases. These include social services that enable the patients to cope with daily life; cope in kindergarten, school and the possibilities to find a job.

In April 2015 representatives from Frambu attended the first workshop called: “Integrated care for persons with complex disabilities produced by rare diseases, using Norwegian model”. The representatives from Frambu were the head of the department for kindergarten, school and summer camps and a special educator with a special responsibility of the schoolwork at Frambu. During courses at Frambu the children and young adults do some schoolwork, but the main goal for these activities is to get to know each other and share experiences about the rare diagnose which is the focus of the course. They are joined by professionals who have knowledge about life having a rare disease and can answer questions from the children and the young adults.

The main focus of all our work is to enable our patients to be integrated in the society and to empower them further in life. The society needs information and knowledge about rare diseases in order to include the patients in the mainstream society as far as possible. During discussions and examples at the workshop, Frambu’s representatives stressed the importance of integrated care for patients with rare diseases.

Frambu’s representatives highlighted the importance of the summer camps for children and young adults as an important tool in the empowerment of the patients. These camps challenges the patients with different rare diagnosis to leave the parents for a short period, to attend activities both indoors and outdoors that might be for the first time, and to meet participants in the same situation together with the students working as helpers in the camps. Frambu representatives discussed these issues at the workshop in order to support the organization of the summer camps at the NoRo Center.

We continued our cooperation in the second workshop in November 2015. Both organizations

“NoRo - Frambu, partnership for future” Project

could report from the summer camps 2015 and share their experiences. The NoRo Center had arranged camps involving 150 participants in lots of activities, like at Frambu, and succeeded in meeting the patients and their families in the idea of strengthen them to meet daily challenges.



The theme of the workshop was “Innovation in services for patients with rare diseases to ensure continuity care”. Frambu was represented by the head of the department of innovation and documentation together with a communications advisor. An introduction of the state of art of organizing care for patients with rare diseases in Norway was presented. The Norwegian Advisory Unit on Rare Disorders organizes the national services for patients with rare diseases together with 9 centers of expertise. Frambu is the largest center giving services to more than 120 different rare diagnoses and is the only center with a hotel accommodation with 72 beds. Frambu is a private foundation funded by the state through the Norwegian Advisory Unit on Rare Disorders.

For more than 25 years Frambu has experienced the need for information and knowledge about rare diseases in the system of health and social services. The municipality shall ensure that all persons residing there are provided with necessary health services. These include persons diagnosed with rare diseases. But our experience is still that rare diseases are little known to professionals, patients and society. The lack of knowledge leads to lack of help

and coping skills among the professionals that should provide services to patients with rare diseases. Frambu is working continuously to improve the necessary knowledge by arranging courses, both for patients and families, but also specialized courses for the professionals and service providers. We share this need for

information and knowledge with the NoRo Center and have supported them in the concept of arranging these types of courses. As Norway is a wide spread country and there is not always enough time for travelling; Frambu is specializing in providing guidance using video conference programs.

Our experience so far from this type of guidance is that more professionals and service providers from the patient local environment are attending that type of meeting. Because they do not need to travel and spend

one, two or three days away from their working place, just a couple of hours.

Frambu’s experience from more than 25 years of working with rare diseases has taught us that giving people diagnosed with these diseases the proper treatment and best care as early as possible will significantly reduce some of their needs for care in the future. This has been one of the main goals of Frambu; to make the quality of life for our patients as best as possible. This includes teaching the caregivers about the diseases and the best treatment, and to help the patients and the families how to cope with the diseases. We have been privileged to share our experiences and knowledge about this important work with our partner in Romania.

Our two countries have by receiving the EEA/ Norway Grants been given a golden opportunity to learn about each other, establish friendship and means of cooperation. To work and cooperate without borders is an important part of Europe’s future. Patients diagnosed with rare diseases have the same needs regardless of which country they are citizens.

Lisen Mohr, Frambu Center

WORKSHOP BILATERAL I

Integrated care for persons with complex disabilities produced by RD using Norwegian model | 28 to 29 April 2015

The purpose of organizing the workshop is to strengthen bilateral relations NoRo – Frambu and share experience in approaching rare diseases in Norway, finding solutions for adaptation the NoRo Center activities using the Frambu model. Given that, the workshop was held in late April, we gave a great deal of time on the debate on organizing the first summer camps for beneficiaries from NoRo Center. On behalf of Frambu participated Karsten Barton, Lisen Mohr and Simen Aabo, representatives from RPWA, other social, medical service providers, colaborators of the NoRo Center and representatives of local authorities. It was made a presentation about the project goal and objectives, how the activities were designed to achieve our objectives.

The workshop was attended by 53 people, including 3 participants from Norway partners. The workshop was held during two days.

The first day after the introduction and presentation of the participants, the workshop was opened with thanksgiving to the partner representatives and authorities present at the event. Collaborating with everyone present that makes possible the development of NoRo services and the improvement of quality of life of persons with rare disease. The project “NoRo – Frambu partnership for the future”, was presented through which the event was organized.

The topics of the workshop were:

- Why we consider the NoRo – Frambu partnership sustainable;
- The Norwegian model;
- Services of Frambu Center;
- Why is integrated care important for patients with rare diseases.

It was studied the possibility of implementation of the Norwegian model, with the specific necessary adjustments of the NoRo Center. It was also presented the structure of activities for people with rare diseases from Frambu Center, including the structure of activities, interventions and personnel, budget and insurance required.



On the second day, starting from the presentation “Patient’s pathway in social services”, discussions focused on the needs of people affected by rare diseases and on how to make better use of community resources, networks, and exchange of best practices. There were several open discussions, than in the first day to give the possibility to participants to find out details regarding the activity of Norwegians. Discussions included the purpose and structure of the camps organized by Frambu Center, justifying their necessity. The purpose of these camps, beside offering enjoyable moments is to strengthen children/young people affected by the disease to develop support groups, to be appreciated and encouraged in what they do, to develop their personality and socialization skills in order to have a better life. However, it is important that the camp activities to be social activities, and not actual therapy activities.

Almasi Zsuzsa, manager assistant

SUMMER CAMPS

Frambu Center and NoRo Center

Frambu Center organizes camps to provide holiday experience, learning opportunities, and activities in a safe environment, with the purpose that these gained experiences to be used in leisure time and everyday life to overcome the challenges they face.



For participants the main objective is often to know other people in the same situation as themselves, to share experiences and socialize. Each camp has 2 camp leaders, 2 leaders of activity, 5 group leaders, about 45 untrained assistants, a medical student and nurse.

Frambu's staff stays in the background of camp life as much as possible, offering advice and counseling to the camp staff.

405 applicants for the job as camp assistant: 30% new applicants and 70% with camp experience. Mostly, young students. 380

applications for participating in total, relatively evenly distributed throughout the four camps. One of Frambu's staff is responsible for the process of employing staff.

Perspectives for participants: learn to cope with different situations, acquiring independent life skills and overcome obstacles, take part in fun activities, possibility of integration, homesick, memories for life.

Participants are children, youths, and young adults with rare disorders, without parents, local caregivers, or assistants. 75% of these having Frambu as their competence service centre. The rest are from other Norwegian competence services. During summer are organized 4 camps, 50 participants (12 - 16 years, 16 - 30 years, 14 - 20 years), 30 participants (18 years and up).



Through many years of organizing summer camps, Frambu has developed a certain “camp culture”, which is passed on from one year to another.



difficulties in completing tasks. Meanwhile parents attended the activities and only where it was the case they intervened occasionally.

During the 5 days, we conducted various fun and enthusiastic activities for kids. This camp was an opportunity for parents to interact among themselves, to know each other better, to make friends, share experiences and find solutions to the difficulties they face in everyday life. Such experience has enabled parents to relax and enjoy a moment of respite.

We try to preserve this camp culture by finding the appropriate balance of experienced and new camp workers and participants. This experience assists greatly in assimilation to camp life and culture.

As far as possible, the camps are left in the hands of the responsible, devoted young workers – youth working with youth.

Starting from this model, through the “NoRo Frambu - Partnership for Future” project we propose to organize summer camps for children from the NoRo Day Care Center and youth from “Independent Living Skills” programme.

To increase socialization among children and young people with disabilities caused by rare diseases and autism spectrum disorder during the period 27 July – 14 August 2015 we organized 3 camps. The first NoRo camp was held during 27 - 31 of July 2015, the second camp was held in 3 - 7 of August 2015 and the last camp took place in 10 - 14 of August 2015. Location Pension “Piece of heaven”. In the three camps, we had 152 people (an average of 50 people per group): 45 beneficiaries and 107 attendants (family members, personal assistants), volunteers and the NoRo team. Volunteers during activities offered help and support to children or young people who faced

This respite was facilitated not only by the conditions in the camp but also by the help of volunteers. Volunteers have an important role in this camp, primarily because during activities each worked one on one with the child, which they received at the beginning of camp. The role of “shadow” of volunteers facilitated stimulation



and management of activities. Children and young people involved in activities benefited from a different kind of therapy in order to acquire social skills, to develop language, to acquire skills of personal autonomy. Outdoor activities in a new environment helped children in the process of adapting to new situations.

Darko Hortensia Emese,
special education teacher RPWA

Parent's impressions about the summer camp



For both children and parents this week was relaxing with a lot of fun activities. We thank to the volunteers who helped us, they really got involved and participated with our children in all of the organized activities.

Words are not enough to thank those from the NoRo Center, that we had the opportunity to take part in a camp organized so nice.

Apetrea Rodica,
Andrei's mother



We had a very beautiful week and we felt wonderful. We are thankful for the accommodation, food and the NoRo team, who take care not to miss anything.

For us this week was one of relaxation, I interacted with many parents, have had many enjoyable activities.

Goia Simona,
Sorin's mother



This week we felt very good, it was nice, the children had a lot of freedom, many enjoyable activities. I had the opportunity to communicate with parents of other children, with whom I shared interesting experiences.

For children was a good opportunity to socialize and interact with other children, to play anything else beside the daily routine activities.

Giurgiu Raluca,
Iani's mother

Dear and innocent little people

There comes a time in every person's life when we feel the need to do more than a small donation or to help an old woman cross the street. For me, this desire determined me to enroll in a post-secondary school, to specialize in the noble profession of balneo-physio-kinetic-therapy. However, fate decided it is time for a deeper involvement, at that time an unknown zone, in the world of the good people and wonderful children from Romanian Prader Willi Association, who unfortunately need our help. Therefore, I started volunteering, that I will never finish doing.



The greatest satisfaction as a volunteer, in activities such as camp, is when you see the smile of contentment appeared on the faces of parents and children involved in inspiring activities in a new environment, but safe, thanks to you and others like you. When you hear his mother exclaiming: “he drew notes on the staff? he drew so beautiful?” or when taking his small hand firmly, feel that his going to fall and by preventing that, you know that you are the reason why is not hurt. Moreover, you understand that you reach his soul, when in his free time wants to stay with you, or when, gone for a minute after the material, seeks you until he finds you.



In the summer of 2015, I got involved in “NoRo - Frambu partnership for future” project and in the summer camps organized by NoRo Center. With the summer sun above us, parents, children, professionals and volunteers, thrilled but smiling, we began our activities. The first day is always special, gathers unspoken questions, curious looks, stories told who knows how many times, in addition necessary to create links between us. Each volunteer received the responsibility to handle one of the children, but without ignoring general needs, other participants present. The camp involves a place where large groups of different personalities come to socialize, cooperate, and carry out activities together, and all of this requires mutual trust. We have tried to become a united group and play for these dear and innocent little people, parents ... and because we knew that, it is possible!

Maybe at first I did not understand all the implications and benefits of participation of all children, parents and volunteers in a camp, but after I saw the change. I have seen parents who come to the Day Care Center with children that talk to each other, which never happened before, I saw children who recognize each other on the hallways or react positively to one another during ergo therapy. In addition, I saw that they recognize us and respond warmly to us, volunteers.

Beyond the story, there are needs, concerns, and fears. Beyond the story, there is a cruel reality, of the children with special needs. Beyond all this, there's us the humans. Taken separately we not always manage to gather the necessary strength to face the current day, but as a community, child-parent-therapist-volunteer we are a force, we force fate and bring back the childhood where seems to be missing. Being a volunteer means to be part of the community that means a lot. Moreover, this feeling is priceless.

Sârbu Sebastian Dușan, volunteer

BILATERAL WORKSHOP II

Integrated care for persons with complex disabilities produced by RD using Norwegian model | 20-21 November 2015

During 20-21 of November 2015 in Zalau, was held the second bilateral workshop under the “NoRo – Frambu, Partnership for the Future” project - “Integrated care for persons with complex disabilities produced by RD, using Norwegian model”.

The topic: Innovation in services for patients with RDs to ensure the continuity of care

The workshop was attended by a total of 53 people, of which 2 participants were from Norway partners. The workshop was held during two days. On the first day, the NoRo Center was visited which was followed by the plenary session. The Norwegian ambassador in Romania Mrs. Tove Bruvik Westberg and representatives of national and local authorities held the opening address speech.

The topics of the workshop:

- The story of a partnership: NoRo – Frambu (video presentation);
- Joint Presentation: NoRo – Frambu partnership for the future;
- Organizing care for patients with rare diseases in Norway (Norwegian model in rare diseases – Norwegian Consultative Unit for Rare Diseases);
- Collaboration between stakeholders only solution for rare diseases;
- The importance of training providers for people with diseases;
- Funding of social services from the authorities.

On the second day were outlined as key concepts: rare diseases, integrated care, centers of expertise, European reference networks, and case studies. It is crucial to refocus medical care to integrated care for rare diseases, centers of expertise and European reference networks. In addition is very important to take into account the recommendations on quality criteria for centers of expertise for rare diseases. These recommendations help in the development process or policy making on national strategies and plans for rare diseases.



The presentations included:

- Case studies on best practice examples, the Rheumatology Clinic of Cluj-Napoca was presented;
- Camps for people with rare diseases in Norway and Romania;
- Accreditation and licensing of social services;
- RARE Project Connect.

It was made a parallel between the camps organized in the summer by the Frambu Center and camps organized by NoRo Center. The conclusion was that these camps were a success among people affected by rare diseases. Sharing experiences by Frambu Center was a first step, which helped organize and conduct the NoRo camps.

Providing holistic services for rare disease patients may represent a number of challenges for patients due to obstacles created by the complexity of the disease, lack of treatment and the rarity of disease. In such situations integrated care aims to improve the quality of care especially when patients have no treatment. Accreditation and licensing of social services provides the ability to easily access specialized social services.

At the end of the workshop was highlighted the importance of collaboration among specialists, patients, therapists or other stakeholders to raise awareness of the needs of patients affected by rare diseases and to support them in trying to find more efficient solutions.

Almasi Zsuzsa, manager assistant

Information and consultancy visits at general social assistance departments in various counties on rare diseases

During the 14 months of the project we initiated collaboration with general social assistance departments in different development region (one service in each region) to inform about the services which NoRo Center can provide for people with disabilities produced by rare diseases and to seek ways of collaboration for their orientation to needed specialized social services.



These visits are a win-win approach: on the one hand, we promote and inform about the center's services, we provide information about rare diseases and find out what problems these institutions face when encountering difficult cases of rare diseases. On the other hand, we want to provide support in their work, trying to identify social services that could integrate patients with rare diseases, giving them information, and training. Information visits in Satu Mare, Alba Iulia, Craiova, Bucharest, Constanta, Timisoara, Pitești, Botoșani. The participants of these meetings were representatives of local or county authorities, providers of medical, social services, and representatives of patient's organizations – actors involved in the management of rare diseases.



On the meetings were raised different issues faced by the people affected by rare diseases:

- lack of services in rural areas and that patients are not interested in statistics and costs of services, they must have access to the services they need;
- the role of communication and collaboration between patient organizations, that signals the needs faced by patients and specialized service providers, policy makers and local community authorities which must develop support tools for people in need;
- specific problems of people affected by rare diseases and different possibilities for collaboration between those present. Discussions were focused on the importance of centers of expertise, stressing that the Order on the organization, functioning and methodology of the certification on centers of expertise for rare diseases, has been approved, good news for all those interested in the problem of rare diseases.

To improve access to specialized social services for people with disabilities caused by rare diseases in Romania, it was popularized the work of NoRo Center and its development objectives after the Norwegian model – Frambu Center.

The Noro – Frambu mentoring program

The Romanian Prader Willi Association in partnership with the Frambu Center for Rare Diseases Norway runs the project: “NoRo – Frambu, partnership for future” financed by the EEA grants Programme 2009-2014 through the NGO Fund in Romania.

The project aims to increase the access to specialized social services for people with disabilities caused by rare diseases in Romania.



Objectives:

1. To strengthen the role of NoRo Center as social services provider, for 360 people affected by rare diseases in Romania in a 14 month period;
 2. To implement a mentoring program together with Frambu Center for RD in Norway, in a period of 14 months;
 3. To develop and asses an innovative approach to ensure continuity of care for patients with rare diseases in Romania – creating a reference networks for rare diseases at national level.
2. Continuously promote the services provided by the NoRo Center by making an awareness campaign and a fundraising strategy.

Project implementation period is 14 months. Funding of the project is 147.867 eur, representing 76.85% of total eligible costs. Our partner in this project is Frambu Center in Norway.

Through the development of integrated and specialized services for patients affected by rare diseases and their families, organized in a national reference network for rare diseases, will allow us to better answer to the specific needs of the target group, will improve access to services and will streamline our interventions.

The mentoring program supports the employees from the NoRo Center by creating a platform through which they can access professionals in their areas of interest from Frambu Center.

RPWA organization development aims two major objectives:

1. Improvement of research capacity by hiring a specialist with experience, in conducting research projects on rare diseases and achieving a portfolio of research projects, followed throughout the project to initiate more research on the social impact of the disease on the families from the project;

The mentoring program will focus on the following areas of common interest: therapies, the program for organizing the patient groups, camps and recreational therapeutic activities, relationship with authorities and community involvement, joint research projects. The mentoring program will be initiated at the meeting in the first workshop, organized in the project, and will be implemented throughout the project.

The program aims to facilitate the transfer of knowledge and expertise between Frambu Center in Norway and NoRo Center in Romania.

Objectives:

1. Updating therapy program for children during the summer;
2. Organizing “NoRo- Frambu” groups for organization development;
3. Organizing summer camps;
4. Development of joint research projects;
5. Promoting permanent partnership at national and international level.

Activities through which objectives will be achieved:

1. The organization of videoconferences & press conference;
2. Participating partners at 2 Workshops and 1 National Conference;
3. Skype Conferences;
4. The use of international events to organize face-to-face meetings to update information on project implementation;
5. Frambu partners participate at workshops, and final conference of the project.

In the workshops will be explored the possibility of implementing the Norwegian model, with the necessary adjustments specific to NoRo Center. It will be reorganized the activities from the center, and organized in other locations. It is proposed that more specialists from NoRo Center to go

to Frambu for exchange of experience, and will we get funding for this activity from other sources than the project (in the project was not provided).

It was analyzed the purpose and structure of the camps organized by Frambu and justifying their necessity. The purpose of these camps, beside offering enjoyable moments is to strengthen children/young people affected by the disease to develop support groups, to be appreciated and encouraged in what they do, to develop their personality and socialization skills in order to have a better life. However, it is important that the camp activities to be social activities, and not actual therapy activities. Given that in the Frambu Center, where beneficiaries of the camps are young people and the specificity of the diseases of the children from the NoRo Center is from autistic spectrum disorder, the decision is that in the following years to organize camps for children with parents and volunteers. Step by step in time to organize camps in which to participate only children, unaccompanied by family members, only with volunteers and NoRo staff. In addition, it was decided that the location should be closer to home. The implementation of the program for camps means to permanent communicate with the experts from Frambu.





Frambu Center will send information on how visits will be organized in the community, meet families who have a diagnosed child with a rare disease and meetings with local authorities or social services, health and education, following that in 2016 to organize such visits with a higher frequency in different regions of Romania. Will be identified financial resources to carry out these activities and the persons responsible.

Frambu Center will decide who will be the participants in the project events and NoRo Center will send the information in advance so that these visits will be organized without creating problem. Currently, rare diseases represent one of the priorities of researchers in medicine. According to the estimates, there are 450 new therapies in research and development, to help patients with these disorders.

In Romania, diagnosis and treatment is precarious compared to other EU countries. In Romania, about 8% of the population is affected by rare diseases, but many patients do not have a full diagnosis and therefore do not receive any appropriate treatment. "Genetic diseases, important category of rare diseases, often-unknown causes, and clinical picture differs greatly, making them difficult to diagnose and treat. Therefore, genetic researches, which

represent the future of medicine, have become a priority for the medical scientific community. Therapies for rare diseases significantly put their imprint not only on patient's lives, but also on the costs of health care. People who suffer from rare diseases that benefit of an appropriate treatment given at time, have the chance to have a normal life. And this leads not only to improve the quality and life expectancy, but also reduce expenses in the health – reducing the cost of hospitalization, treatment complications, psychological counseling, and palliative care".

Starting from the Norwegian experience in the field of integrated care for rare diseases, we plan together to identify joint research projects:

- Impact assessment of patient care in Frambu Center and NoRo Center;
- Conducting studies of history of diseases from families experience;
- Impact assessment of the therapeutic education programs on family resilience.

Will be identified research projects that we apply in partnership. Organize awareness campaigns on Rare Disease Day Campaign 2016 and the celebration of 5 years of activity of the NoRo Center in June 2016.

Dorica Dan, project coordinator RPWA

Impressions of the journalists present at the Rare Disease School for Journalists 2015

The greatest job satisfaction as a journalist is certainly the certainty to realize that you managed to change something in yourself by what you do. Beyond the running of the daily routine, hundreds of emails, sorting of information, the inevitable work routine, there are some moments that ensures that the efforts it does have an echo in making his way through the few minutes that the reader sacrifice for reading your words.

Oana Mărginean, The Voice of Transylvania

Until recently, when I had heard the word NoRo my thoughts were about a movie with a sad and shy boy. Some years passed since the story of the movie, when I found out that NoRo is not a movie, exists in reality. However, it's not a boy, it's a wonderland. I dare to say even slightly charmed. Because children come here sad and shy, like Noro, the movie, and through magic they become happy and show interest in everything around them.

Sorin Șchiopu, Radio Romania Targu Mures

I avoid looking out the window to not destroy my feeling of “another world” that gives me the inside of the NoRo Center in Zalau. I prefer instead to admire the woodwork of windows kept inside to show that we are in a 200 years old building. It is hard to imagine that such a thing exists in Romania. Patients who come here benefits of different therapies such as behavioral therapy, speech therapy, sensory therapy, physical therapy, jacuzzi, multifunctional rooms, accommodation like in a hotel with many stars and because addresses especially the children, a playground outside with facilities.

Andrei Hutan, Radio Romania Cluj

Rare people are those wonderful people who accompany us on the road of life to make our heart better and happier. These wonderful people are yourselves, who have opened the way to our soul to understand you better, burdened by the difficulties of life and our needs. You are rare because you are special in everything you do, transmit and give.

Ionela Chircu, Journal of Ilfov

I had the honor to visit the center, to meet patients with rare diseases, happy that they found a landmark and solutions without knocking door to door, perhaps unsuccessfully, we met glad parents that their children have made progress - standing, go by themselves, they learned independent living skills. In addition, all this with the help of qualified staff and specialized services offered in medical offices, equipped with modern devices, in spaces specially equipped for physiotherapy, speech therapy, hydrotherapy, occupational therapy, sensory therapy, behavioral therapy etc.

Arina Moldovan, Magazine Medfarm

I was under the belief that you can feel nowhere better than home. Where you have family around you, where you feel loved and protected. From the moment I stepped into the NoRo Center, I noticed with pleasure

that I was wrong. This place exists and you can find parental love and care, even if there is no blood relation. Moreover, makes me want to applaud because they see that there are people who will not stop fighting for them and others like them.

Dana Lascu, Daily Event

A new gold mine was opened in Romania, Zalau. This artisans, a family “with a big heart” Tiberiu and Dorica Dan, by the success of which depends the fate of many rare people. Rare people, because they have the misfortune of being owners of rare diseases. NoRo center offer the following therapies for rare diseases, behavioral therapy, sensory therapy, speech therapy, hydrotherapy, massage, physiotherapy, occupational therapy, music therapy, art therapy. It is a model of success in tackling rare diseases that apparently can move things in this area.

Dan Dumitru Mihalache, Medical Life

Hello! I am Rett. I am a syndrome. I was born eight years ago, the same day as Andrew, but I made my presence felt only after two years of life. The doctors discovered me much later. We are few in the world and it seems little like other families. Andrew lives in his own world, I in his body, my world. We live in the same world, yet in parallel worlds. Andrei is small in height, has small hands, cold and nervous. He does not like socializing. I am just his friend. I do not know what I look like. There are no mirrors. I see only through the eyes of those who looked in the eyes of Andrew. I think I am ugly, because sometimes other children mock us. Several times a week we meet with other children who experience the same thing. We go to a center in Zalau, only dealing with rare diseases in Romania. Andrew's lucky that was born in Zalau, but unlucky that we were born together.

Maria Man, Transylvania Reporter

NoRo Center, Zalau? Nothing easier: you must call and get an appointment in the future in a group of 12 to 14 patients with the same disease. In a year, gather over 140 patients benefiting from these services. Patients with rare diseases, whether child or adult, is optimistic, a fighter and learned that the only support is the family, the good God, and Dorica Dan is for such children a guardian angel for one reason: he managed to raise in Zalau the NoRo Center.

Vlad Tătaru, Radio ProDiaspora

“Every case is special, different. Each is spectacular by what succeed to do. We have children who are unable to speak, they fail to speak at an advanced age, we have children who are unable to walk, unable to move or to express needs. We cannot talk about something general in children with rare diseases” said Emanuela Ghile, speech therapist at NoRo Center.

Carmen Ile, Bihor.ro and Bihorean Journal



- A sustainable partnership
- Improved organization management

- Updated information about rare diseases
- Capacity for diagnosis and research developed

- Equipment purchased (EMG, ECG, Body fat monitor, Ultrasound, MIRA, Deep oscillation, laptops)

- Staff trained in first aid, management of the project and acquisitions

- 8 information visits made
- 3 organized camps
- 4 patient groups organized



- Information and promotional materials made and distributed
- 4 meetings with other services in the community made



www.eeagrants.org
www.norwaygrants.org

- 4 partnerships, to ensure continuity of patient care
- A mentoring program developed
- Map Services Printed

- Exchanges of permanent information and experience
- A reference network for patients care with rare diseases



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