



FUNDACION RUACH

Fundacion Cristiana Comunitaria para Personas con Discapacidad

7th Ruach Newsletter: May 2019

The main theme of this Newsletter is the experience our Foundation has in seeking medical care for our intellectually disabled core members. In a poor country like Nicaragua most people struggle to access the health care they need, but for Intellectually Disabled Adults (IDAs) the barriers are even higher. Therefore it is not a surprise that Ruach staff members have had difficulties ensuring that our core members get the medical care they, like anyone else, deserve. Nonetheless, the difficulties Ruach faces also more than offset by several stories of amazing and generous support from people of good will that give us joy and hope.

In 'other news' we pay tribute to Jean Vanier, the founder of The Ark International who has inspired Ruach's work who died on 7th May 2019 and the recent visit of our coordinator, Astrid Delleman, to Holland and the UK.

MEDICAL CARE FOR OUR CORE MEMBERS

Ruach does not ask for health status or medical records when recruiting members for the Community Home. The core members come as they are, determined by genetics and the (medical) care they had before they joined us. None of Ruach's staff members are medically trained, so we have to deal with medical issues among our core members the best we can, but we are greatly helped with advice by a doctor-friend who is part of our godparent network. In the past six months we have had to handle Daniel's psychotic behavior, Loyda's infected teeth, and Maria and Manuel's eye sight. In some cases there is a straight-forward medical solution, in others it is a matter of alleviating the symptoms as much as we can and adjust to the circumstances as best as we can.

Loyda's visits to the dentist

The majority of people with an intellectual disability, including our core members, have never seen a dentist, no doubt partly because they were not able to indicate when they suffered toothache. So we should count ourselves lucky that the teeth of our 'men' (Daniel, Miguel, Manuel and Jonathan) look quite good. Unfortunately, the teeth of Maria Helena and Loyda look less strong, and at their relatively low ages they are already missing several molars and incisors.

As Loyda had been suffering from bleeding gums, we asked her mother, doña Yolanda, to take her to the dentist in the hospital which treats patients free of charge. She came back quite indignant: the dentist had not even looked into Loyda's mouth and

had told her to use a spray to stop the bleeding and to return after one month. No good!



Through a doctor couple, who happened to be on a visit to Juigalpa to get to know our Ruach Foundation, we got the address of a dentist related to this couple. Dentist dr Baez was able to see Loyda three days later. Although private dentists have their own practice and their own prices, dr. Baez immediately offered us a reduced fee. It was difficult to get Loyda to open her mouth wide and long enough for the dentist to properly assess Loyda's dental status, but it was obvious she was suffering from an infected bad tooth and poor dental hygiene. Treatment would be easiest if it could be done under a general anesthetic, which would require a test whether Loyda would be able to undergo a general anesthetic, the presence of two dentists and an anesthetist and a bottle of oxygen.

Loyda's blood test was arranged at the local lab through our doctor-friend and indicated it was safe for Loyda to have a general anesthetic. A female friend helped us by driving a very heavy bottle of oxygen from the doctor's practice to the dental clinic. A few days later Loyda was back in the dentist's chair, surrounded by two dentists, Dr Baez's wife, the anesthetist, doña Yolanda, and myself. Dr Baez himself was in the US for a week, but he made sure his colleagues would give the treatment free of charge, and before the procedure started he prayed on the phone and asked for a blessing for the operation. It was a special and moving moment which was followed by a one-hour operation that involved pulling three teeth and giving her mouth a pretty thorough clean.

We had not thought of getting Loyda back home after the operation, so I had to arrange this on the spot. Again, 'good befell us': Jorge collected her in his car. And because he is also a doctor, he stayed to give Loyda her injections (anti-biotic and pain killer) which we had bought in the local pharmacy. Jorge came back the next day to repeat the injections, saving us the trouble and cost of finding a nurse to do this.

Loyda is still recovering. She slept the first night sitting upright to avoid the risk of choking. For days she only wanted to drink, was tired and weak. But more 'luck' came our way. The owner of the pharmacy accepted our written request to donate to us an expensive gel that promotes Loyda's recovery. We're hopeful that Loyda will soon be back to her 'old self'.

Maria Helena and Manuel's eye-sight

Siblings Maria Helena and Manuel who joined Ruach as core members in December continue settling in well in the community. However, as we mentioned in the Feb 2019 Newsletter, their eyesight is a worry that requires investigation. Therefore we had registered the two of them with the Lion's Club, a charity which annually tries to motivate a brigade of American eye doctors to come to Nicaragua to give access to good eye investigation and cheap glasses for the not-so-well off. But unfortunately, due to the increasing international condemnations (OEA, EU and US) about the political situation in the Nicaragua, the visit of the eye doctor team was called off. As we could not wait for the team's next possible visit a year later, we checked out eye doctors in our area and we got in touch with one with the best reputation who usually charges \$15.00

for a consultation. When we requested a reduction, he said he would not charge us at all!

However, the results of the investigation were not hope-giving. He concluded that before their birth during their mother's pregnancies something had gone wrong which has caused a serious impairment of their sight, and it cannot be treated. Nor can special aids be used to improve their sight.



So we are left with the task to work out what they are able to see at varying distances, and to take that into consideration. The challenge now is to give them a chance to gain as much control over their life by supporting them only in the most necessary situations.

Daniel

Ever since Daniel joined us he sometimes shouts during the night. We cannot work out what causes this, because Daniel does not talk or talks in a manner we cannot understand. In December the shouting got so bad that he kept other house mates awake. We assumed it was psychotic behaviour so we called for a psychiatrist who lives in our street. There and then she prescribed tranquillizers to get him through the night. The next day she saw Daniel and his mother for a consultation in the hospital where she works. She asked many questions, but did not explain much. She gave us a referral note to get an EEG made which could rule out that Daniel is epileptic. However, when we visited the hospital in Juigalpa to make an appointment we were told that we would have to go to Managua for an EEG. Daniel was put on the waiting list, but we are still waiting from the hospital in Managua. In the meantime, we got the EEG done, free of charge, through the mobile brigade of doctors of Los Pipitos, a charity that works for families with intellectually disabled people. The result...? Daniel has not got epilepsy, but we are none the wiser about his shouting of confused language. We would want to avoid giving medicine as much as possible, but we do give him a tranquilizer when he talks when he falls asleep or shouts when he is asleep. His and a good night's sleep for all other residents is important to us.

ASTRID'S VISIT TO HOLLAND AND THE UK

Astrid Delleman, the coordinator of Ruach's Community Home and Activities Centre, was in the Netherlands and England from 15th March to 3rd April, partly to promote Ruach's work

* On 24th March she addressed the service of the ecumenical church community 'De Regenboog' (Rainbow) in Leiden. The church service had a special Latin American flavour as the choir had rehearsed some songs in Spanish. The collection during the service was also for Ruach's work in Juigalpa. The proceeds will be used to buy learning tools that will further and widen the development of the core members of the Ruach community. The learning tools will be chosen in collaboration with the physio-therapist of the hospital in Juigalpa.

* On 19th March Astrid she made a presentation about Ruach's work at a meeting in Sherborne. It was organized by UK Ruach 'ambassador' Eric Jager and his wife Rosaleen to say thank you to the Anglican Parish which has supported Ruach every year since 2016. Astrid wrote afterwards: "It was heartwarming to meet with a group of about 30 people and to sense their involvement. The cherry on the cake was that the donation box, to which no particular attention was drawn, contained £270 for our work!"

* On 27th March Astrid attended a dinner in a somewhat unlikely place, a forensic psychiatric clinic, to talk about Ruach's work with the inmates and visitors of the clinic. One of the inmates is a close friend of hers, and Han (not his real name) who loves cooking, had started 'Loyda's café' during Lent 2018, named after one of Ruach's core members who also was hidden from society before she became a core member of Ruach. Since Lent 2018 Han has kept the café going once every two months with attendance ranging from 20 to 50. On this occasion Han cooked for 30 people who afterwards contributed a fine € 385 for Ruach's work. In addition, Han and his friends also prepared a gifts (a rucsac) for all core members of the Ruach Home and the participants of Ruach's Activities Centre! Truly inspirational.

NICARAGUA UPDATE

In spite of being off the headlines the situation in Nicaragua is not peaceful. Daniel Ortega's Government faces continued sanctions from the international community. The Organisation of American States has expressed deep concern about the political situation. Negotiations between the

Government and several organisations representing the people (called Blue and White) are on-going, but have not yet resulted in agreements being implemented. Please keep remembering Nicaragua and its people.

JEAN VANIER, FOUNDER OF L'ARCHE, WHO CHANGED LIVES OF INTELLECTUALLY DISABLED WORLDWIDE, DIES IN PARIS



In our 5th Nov 2018 Newsletter we wrote about how Ruach is inspired by the work of The Ark International, and in particular by its founder, Jean Vanier. This giant of humanity and humility died at age 90 on 7 May in a L'Arche facility in Paris after a short illness. For a moving account of his life and work for and with intellectually disabled adults, please browse for this article:

<https://www.ncronline.org/news/people/jean-vanier-who-changed-lives-intellectually-disabled-dies-paris>

"Jean Vanier's great gift was his amazing trust in people," says Sr. Sue Mosteller, who worked with the L'Arche Daybreak community in Toronto for four decades. "He trusted others to be responsible. Jean emphasized that when new projects were started, the organizers all have options. But if it fails, people with disabilities don't have options, and that's why we have to work hard to make sure we have a stable foundation."

We at Ruach will continue working hard to create such stable foundation for our young organization as our wish to eventually join L'Arche International as the first Ark community in Nicaragua is as lively as ever.

You can support our work by writing to us at our new email address fundacionruach@gmail.com, or to make a financial contribution through either:

1. Global Giving (in £, \$, or €):

<https://www.globalgiving.org/projects/fundacionruach>

or: 2. Vivir Juntos (in €): www.vivirjuntos.nl

Your involvement means the world to us.