



REKAT

FEARLESS SPIRIT

High spirit and enthusiasm are things that make life more dynamic and meaningful. When that kind of spirit is backed by conducive positive energy and creativity, undoubtedly, we can get through all obstacles we face.

The MDR-TB peer educator society has been established in Surabaya since 2012, then later in 2014, the group chose the name "REKAT" or Arek Nekat¹ for short. We often hear the word "arek" itself in terms such as "arek Suroboyo"², which in the Surabayan dialect replaces the word "bocah" or kid in the standard Javanese language. The type of fearless spirit here refers to fearless in fighting the side effects of MDR-TB treatment which the patients must go through more or less for 2 years. "REKAT"³ can also be defined as friends come close or become tight with other patients, so they will feel comfortable in sharing the difficulties they face while undergoing treatment," Indra Riesdianto stated, a KNCV social worker who all this time has been accompanying the health staff for the MDR-TB peer educator program at Dr. Soetomo Regional General Hospital.



Rekat's activities, which consists of 15 members, are many, ranging from psychosocial support, Communication, Information and Education (CIE) and accompanying

patients. REKAT also organizes breathing exercises for the patients once a week. Outside of patient related activities, REKAT is also learning to financially support their organization by making handicrafts.

Some of the handicrafts produced by REKAT are brooches, dyed fabric made up from natural and synthetic material, silk screening and even publishing their own bulletin. Gazebokita, is the name of REKAT's bulletin, which is published once a month and priced at Rp.30.000, where every Rp10.000 is donated to conduct programs specially designed for MDR-TB patients.

The name Gazebo is nothing new to the TB patients at Dr. Soetomo Hospital because there are three gazebos at the TB polyclinic. Gazebo A is for new patients, Gazebo for converted patients, while Gazebo C is for patients already in continuation phase.

Proceeds from their handicrafts and bulletin have enabled REKAT to donate one wheelchair and a refrigerator for the patients. In the future REKAT, which is now in the legal process to becoming a legally recognised organization along with the assistance of KNCV, plans to keep on accompanying and motivating patients while at the same time keep on producing works for the advancement of the organization. In closing this meeting with REKAT, I want to quote the fearless spirit of its chairperson, Mrs. Tati: "It's better to suffer for 2 years than suffer a whole lifetime". [TR]

REKAT'S PERSONNEL



This madam who is usually called Tati, is the current chairperson of REKAT. She at one time underwent alternative medication, but since 2012 has gone through treatment with a medicated program and has recovered from illness in early 2014.



Aruna Pradipta, went through TB treatment in 2010. Her MDR-TB treatment was completed in 2014. She is now an Aisyiyah⁴ staff for patient counseling.



Coming from a heavy smoker background where he could smoke up to four packs of cigarette a day, Mr. Abu was diagnosed with MDR-TB in 2010. He is the 17th patient out of 25 to be cured at the beginning when the MDR-TB polyclinic first opened at Dr. Soetomo Regional General Hospital in 2009. Apart from being active in REKAT, Mr. Abu is now a Aisyiyah staff for accompanying patients. He is also a former chairperson of the MDR-TB society in 2012.

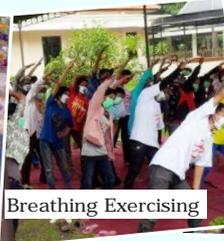


Mrs. Ani Hernasari was diagnosed with MDR-TB in November 2011 and completed her treatment in 2013. Even though she is now 8 months pregnant, she remains active in REKAT. She also learned from Mrs. Sri, a health staff at the MDR-TB polyclinic, on how to make Jumputan or tie-dye batik which is a certain technique of colouring fabric of natural and synthetic material, which she then sells and hand over the proceeds to REKAT. Besides that, she and her husband are the founders and publishers of Gazebo magazine.



Mr. Purwo Khomani, underwent TB treatment in 2007, but because he prioritized his work, he didn't focus on his treatment. This lead him back to being treated at the MDR-TB polyclinic in 2012. Now, Mr. Purwo is a health department staff in Surabaya to help examine patients at various local clinics. Mr. Purwo also trains patients in being productive by utilizing the silk screening method. Each patient who wants to learn about silk screening is given 2 million rupiahs as seed money from the Health Department which must be returned later on.

REKAT's Activities Photo by Indra & REKAT documentation



Foot notes:
 1) The suitable meaning of nekat in this context is fearless.
 2) People who originate from East Java often refer Surabaya as Suroboyo because of their Javanese dialect.
 3) Rekat means to stick, to glue, to cling on to
 4) Aisyiyah is a CSO (Community Support Organization) that is a partner of KNCV

POLIKLINIK TB & TB-MDR



The Dr. Soetomo Hospital MDR-TB polyclinic standing from left to right: Mrs. Alifatur, Mrs. Ramawati, Mrs. Sri, dr. Tutik, Sister Vivin, dr. Nurul. Squating from left to right: Mr. Ikhwan & Mr. Arif.

Mrs. Sri's Story

Starting her career in the OB/GYN department from 17 years, Mrs. Sri Rejeki later joined the pulmonary polyclinic in mid 2011, she is now person in charge of the MDR-TB polyclinic at Dr. Soetomo Regional General Hospital, and has been since 2012.

Now there are 80 MDR-TD patients undergoing treatment at Dr. Soetomo Regional General Hospital.

Here in East Java they have adopted the 6/6 treatment method where the patients are only injected and take medication for 6 days, instead of 5/7. Besides that the MDR-TB patients who are

"For the MDR-TB patients here at Dr. Soetomo Regional General Hospital, Sunday is as though a festive day, because they can eat what they want, gather with their families, so that on the following Monday they feel "fresher" to start their treatment again" says Mrs. Sri.

working can get their treatment after working hours, because the polyclinic is open until 7 p.m. The MDR-TB polyclinic at Dr. Soetomo Regional General Hospital was opened in 2009, and at the

start had only five patients, but after the presence of GeneXpert, there are 1 to 3 positively diagnosed patients per day who are sent to this hospital from referring local clinics.

For patients that fail to come in, the MDR-TB polyclinic cooperates with the social workers of KNCV and REKAT to carry out visitations, CIE, and psychological support.

"...That's TB ma'am, not smear lung ..."

That is Mrs. Lestari Handayani's response, when another madam at her child's school tells about her child's condition.

"According to the doctor, her child has lung spots and must undergo treatment for 6 months, and the medicine is the same as TB medicine which turns the urine into red, so then I said to her that that's TB, and not smear lung" tells Mrs. Lestari. Mrs. Lestari's knowledge about TB is based on her own experience because both her husband and daughter used to be TB patients.

It all started from the husband, Mr. Binsar who was diagnosed with TB. He started TB treatment in 1997, at the time when TB treatment and knowledge was not vast. The doctor never told in detail about the illness he was suffering or the treatment that he

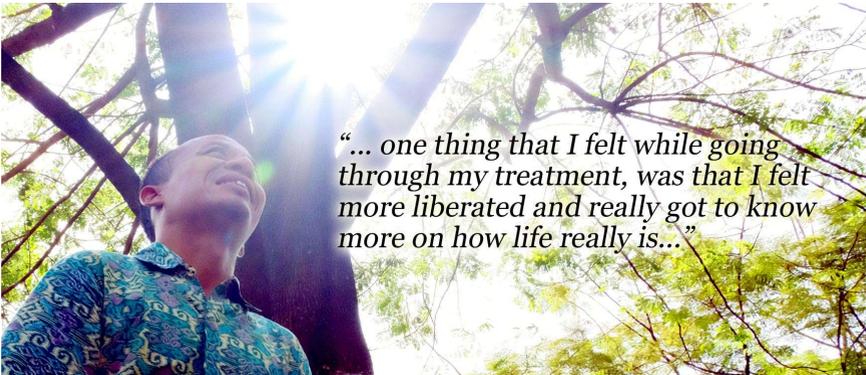
had to go through, in spite of the symptom he experienced was severe, which was coughing blood. Due to that situation, the treatment came to a halt halfway when Mr. Binsar felt he was better. "Then in 2010, I coughed blood again and got myself examined at the hospital, the result came out and I was diagnosed with MDR-TB." While receiving MDR-TB treatment Mr. Binsar began to gain knowledge about TB, one of which was about the symptoms of TB. "And after paying close attention it turned out that my 5 year old child showed those symptoms," Mr. Binsar explained.

"At that time my daughter kept on coughing, she didn't gain weight, lost her appetite, her hands were always sweaty day and night, but one symptom that stood out the most was her coughing that didn't get any better, even after taking

medicine" answered Mrs. Lestari when asked about the symptoms her daughter experienced at the time.

Finally, Mrs. Lestari brought her children to the pediatric polyclinic, and the doctor asked her if there was someone diagnosed with TB at their home. Mrs. Lestari answered that her husband was currently undergoing TB treatment. Afterwards Mrs. Lestari and both of her children had their sputum and culture checked and the results showed that only her first born

daughter went to Solo with her little brother. Her TB treatment there was closely watched by her grandmother. Even under her grandmother's watch, Mrs. Lestari's daughter regularly drank her medicine. She was given powdered medicine, that didn't trouble her when swallowing it. "Even though my daughter asked me why she had to keep on taking her medicine, but she diligently took it" told Mrs. Lestari when asked about her daughter's obstacles in her treatment.



child was diagnosed TB positive. Both Mrs. Lestari and her younger child were found healthy.

"At that time there were two people that had to go through treatment, my daughter and I, and things were tough for us, so we decided that my daughter would continue her treatment in Solo, at my in-laws place" told Mr. Binsar.

Eventually, after 3 months of treatment in Jakarta, Mr. Binsar's

A year passed, and Mr. Binsar's daughter successfully completed her treatment. Then in February 2013, Mr. Binsar also completed his MDR-TB treatment. "One thing that I felt while going through my treatment, was that I felt more liberated and really got to know more on how life really is, the importance of healthy living, the prevention and overcoming of TB" said Mr. Binsar when asked about his experience going through treatment.

Now Mr. Binsar and Mrs. Lestari's daughter is 8 years old, and even though she has completed her TB treatment 3 years ago, Mrs. Lestari still worries sometimes when her daughter has the cough and fever. "One time, my daughter had the cough, so I immediately took her to the local clinic for the phlegm and culture examination but thank God the result was negative" she uttered.

Mr. Binsar and Mrs. Lestari always caution their children about healthy living, not to buy food carelessly and coughing ethics. "I also told my daughter's P.E. teacher that she was once ill, and that she wasn't allowed to play sports excessively and mustn't

get too tired" Mrs. Lestari told us.

Learning from their experience, both Mr. Binsar and Mrs. Lestari are involved in giving education and information about TB disease. Mr. Binsar himself is the member of PETA¹, while Mrs. Lestari also is always ready to give education at her children's school. Recently, Mrs. Lestari advised one of the security guards at school to get himself examined because he often coughed and smoked cigarettes.

On a final note, Mr. Binsar and Mrs. Lestari are grateful for their health and all of this is because of God's gift, "Now, we are enjoying being cured with great joy" said Mr. Binsar.

1) PETA is peer educator located in Jakarta. Peer educator was introduced as a part of patient support approach, and were published in November 2014 by KNCV

