

# RESEARCH REPORT ON NEURO-DEGENERATIVE DISEASES IN BADE, EDERA DISTRICT, MAPPI, PAPUA, INDONESIA — Case Studies on Auyu and Jakay People —

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## Background

- According to Article in Neurology, edition in February 1982, page27, D. Carleton Gadjusek, MD and Andres M. Safazar, MD reported that there were Amyotrophic Lateral Sclerosis (ALS) and Parkinsonian syndrome in Bade and Edera Districts and they were two highly occurred diseases happened to Auyu and Jakay people<sup>1)</sup>.
- According to this report it is interesting to join survey between Kyoto University and Uncen medical teams to do research again on the fluctuation of ALS and Parkinsonian Syndrome.
- If there is an increase or decrease, hence, what are the causing factors.

## Purpose

- Various factors may influence the increase or decrease of the diseases. To answer the problems of ALS and Parkinsonian Syndrome, we joined the surveys held on Okaba in January 2006, and the surveys on Bade in Ereda district in January 2007.
- These diseases frequently occur in Auyu and Jakay people. Hence, the research was focused on environmental and cultural factors (non-medical factors).

## Method

- In the survey data were collected in neuro-degenerative patients and some people were treated in two different areas, Auyu and Jakay people, in Mur villages, Mappi regency and Osso, Bosuma,

Ogorito, Asset, Kobeta, Homlikya, Geturki, Gimikya villages, and in Bade medical center.

- Medical check and treatment
- Interview
  - Patients
  - The family of the patients
  - Paramedic
  - Community leaders
- Observation
  - Observation was done during the survey, medical check and interview in two mentioned locations.

## Results

### · General

- According to Dr. Hery, during his 15 years' duty in Merauke and Mappi regencies, he has never found any ALS and Parkinsonian patients, but he also has read books and seen internet web site, and learned that the occurrence of these diseases was high on Auyu and Jakay people in Mappi and Bade areas some years ago.
- The emerging diseases in Mappi regency are Malaria, Pneumonia, TBC and HIVH / AIDS.
- Stroke and diabetes often occur on non-native people. Native people rarely suffer from stroke and paralysis.
- The knowledge of paramedic in Mappi and Bade public health centers was very limited. They don't know the indications and causes of neuro-degenerative diseases.

• **Specific (Mur village case)**

- The survey held in Mur village, which is located on the River Mappi bank, found 4 patients with different diseases within 2 hours (see table 1).
- According to the data in table 1, food, age, environment, nature, activities and culture are much influencing the patients' health conditions.
- Their beliefs in supernatural powers and matters prevent them from going to medical centers.
- There are habits of smoking, betel vine chewing, drinking local alcoholic drinks, and submerging in the river.
- The suffering body parts were head, knee, feet, and part of left hand in the four patients.
- There is a habit of carrying things on the left shoulder, and having only 1 meal a day.
- Hunting, sago gathering and fishing dominate their daily life from morning to evening.

• **Specific (Edera District in Bade, Public Health Center)**

- The tariff of medical services in Bade community health center is not balanced with the capability

of the people. As a result, the people are less participating.

- There were 7 Auyu patients suffering from the same indication that comprise one paralysis case of Auyu tribe, one patient from Moi tribe, Sorong, two patients from Sulawesi Selatan who work as medical personnel, farmer, fisherman, harbor labor, and house wife.
- The initial indications were the same. Almost all of them started to suffer in 2000 - early 2007. They suffered from difficulty in talking, standing and walk, drooling, and blurred eyes.
- The suffering parts of body were namely partial weaknesses on the left or right parts of their bodies, stress in their feet or hands muscles, skinny, difficulty in moving hands and feet, cold, cramp, difficulty in moving feet fingers and shoulder, pain on back and sudden puffy. (See table 2)
- The cultural view still influences the way of thinking of most of Auyu people in Bade by believing that sickness and diseases are caused by:
  - Self or others deeds.
  - Their bodies are attacked by supernatural

Table 1. Patients in Mur District in Mappi Regency

| No | Initial of Name | Age | Job              | Tribe (Origin) | Initial Indications of the Sickness  | The Suffering Parts of body           | Habit  | Explanation  |
|----|-----------------|-----|------------------|----------------|--|---------------------------------------|--|--|
| 1. | P.W             | 35  | Farmer           | Mappi (Auyu)   | - Fallen from a car some years ago<br>- Eat hot cassava leaves, deer meat<br>- It has been two years | - Left head, knees, feet, and palms   | - Likes to smoke<br>- Drinking alcohol<br>- Fishing in the river                                     | - He never goes to public health center<br>- He regards his sickness as supernatural disturbance<br>- Once fell down |
| 2. | P.S             | 50  | Farmer-Fisherman | Asmat          | - Pain in bones and headache since the last 12 Years<br>- Once was hit/punched                       | - Head, knees, back feet, and hands   | - Walking without footwear<br>- Fishing in the river   | - Got magical offense from somebody<br>- Jealous   |
| 3. | M.M             | 56  | Farmer           | Mappi (Jakay)  | - Drooling while walking   | - Left part of body<br>- Stiff hand   |  | - Got magical offense from somebody  |
| 4. | E.B             | 65  |                  | Jakay          | - Coldness<br>- Chilly<br>- Back pain<br>- Bone pain<br>- Coughing<br>- Since the last 4 years       | - Trembling left hand<br>- Right knee | - Still working in farm even when she is sick<br>- Fishing in the river<br>- Smoking<br>- Betel vine | - Once went to a public health center, but did not recover<br>- A lot to think about<br>- One meal a day             |

creatures living in the jungle and river.

- Their bodies are troubled by personalistic disturbances as a result of social jealousy among Auyu and Jakay people.

- There is a lack of medical treatment for ALS syndrome, parkinsonian and other diseases related to nerves and bones. Therefore, patients who suffer from such indications are treated at home by their family with only very simple treatments.

#### • Specific (Ogorito Village Cases)

- 2 cases were found in Ogorito village with the same indications in their ages of 30-34 years old. Both cases indicated the same signs, epilepsy, drooling,

unable to walk, to eat and to stand, their left part of body was paralyzed. This started when the patient was in the farm alone.

- According to the information from the patient's family, this sickness was caused by a supernatural creature called Kase, because he had seduced somebody's wife or husband. The patient had not done cultural confession and could get worse and could be transferred to his descendants if he is married.

- There is a belief that sickness and diseases will not happen if somebody doesn't do anything wrong towards nature and social cultural environments.

Table 2-1. Patients in Bade (Public Health Center) in Edera District

| No | Initial of Name | Age | Job       | Tribe (Origin) | Initial Indications of the Sickness  | The Suffering parts of body  | Habit   | Explanation   |
|----|-----------------|-----|-----------|----------------|--|--|---|---|
| 1. | M.K             | 39  | Nurse     | Auyu           | - Since 2000<br>- Can hardly talk, stand, and walk<br>- Uncontrolled drooling                    | - Left part of body paralyzed  | - Sit   | - Sick Because of curse<br>- His brother, Damianus Kobogau, suffered from the same sickness   |
| 2. | K.K             | 50  | Farmer    | Auyu           | - Working as a chainsaw operator<br>- Can hardly talk<br>- Drooling                              | - Right part of body paralyzed   |   | - Once went to public health center but did not recover and stayed at home  |
| 3. | S.K             | 50  | Nurse     | Moi, Sorong    | - Can hardly talk since 2000   | - Stiff feet muscle<br>- Feet fingers can hardly move                      | - Smoking   | - Like to drink alcoholic drink<br>- Smoking<br>- Once went to hospital in Merauke, but the sickness occurred again                           |
| 4. | D.B             | 50  | Farmer    | Muyu           | - Can hardly talk<br>- It was started when dig soil for rice field Since 2003<br>- Eat deer meat | - Right part of body, feet and hands<br>- Cramp feet<br>- Cold and stress  | - Working in Saiwa<br>- Dreaming about his dead child | - Once went to public health center but there was not any medicine<br>- he suspects that he got magic   |
| 5. | P.K             | 70  | Fisherman | Auyu           | - October 2006<br>- Blurred vision   | - Foot fingers<br>- Painful bones<br>- Shoulder, left hand can hardly move | - Smoking   | - Like to drink alcoholic drink<br>- Smoking<br>- Once went to hospital in Merauke but the sickness occurred again                            |
| 6. | S.K             | 41  | Farmer    | Auyu           | - Since 2002   | - Waist can hardly move<br>- Cramp hand and foot                           | - Sleep and sit                                       | - Cursed by somebody, because of jealousy<br>- Once went to magician because of the limitedness of medical means in the public health center. |

Table 2-2. Patients in Bade (Public Health Center) and villages around la River in Edera District

| No | Initial of Name | Tribe Origin                           | Gender | Age      | Kinds of Sickness Suffered   | Suffering Period  | Explanation  |
|----|-----------------|--|--------|----------|--|---|--|
| 1  | M.K             | Auyu (Bade)                            | M      | 35 years | Paralyses<br>- Trembling hands and feet<br>- Weight decreases<br>- Can hardly talk<br>- Can hardly go out of the house   | - 2006-2007 (Up to now)<br><br>- Has been 7years  |  |
| 2  | S.D             | Suku, Auyu (Bade)                      | F      | 44 years | - Puffy heel<br>- The pain spreads to all parts of foot in the night time<br>- Painful when walk   | - 2000 - now (7 years)  |  |
| 3  | S               | Makassar (Ujung Pandang)               | M      | 37 years | - Painful back heel  | - 2003 -now<br>- Has been 3years  | - Liked to drink alcoholic drink when young<br>- Liked to drink unboiled water from well<br>- When painful, rubbing the pain area with balm, minyak tawon (bee oil)<br>- 2 descendants:<br>- The first is a son The second is a daughter<br>Both pre-school age                      |
| 4  | R               | Toraja (Sulawesi Selatan)              | M      | 43 years | - Diabetic   | - 2000-now.   | - Cramp on the feet<br>- Defecate and urinate<br>- Pain on both feet<br>- Camp on fingers in the night time<br>- Food consumption<br>- Consume well water and drinking water   |
| 5  | M.D.A           | Auyu (Bade)                            | M      | 62 years | - Diabetic Cramp on both feet<br>- Can't do hard work<br>- Can walk<br>- Can talk<br>- Can listen<br>- Always eat like cassava, sago, banana, taro and etc.  | - The indication started in 1995 - now<br>- Like to consume alcoholic while young<br>- Consuming Everyday meal but Less fat/protein contents. | - 4 descendants:<br>- Three adopted children<br>- 1 real child<br>- Deceased wife<br>- A retired civil serpent   |
| 6  | A.R             | Key (Maluku Tenggara) (living in Bade) | M      | 10 years | - Paralyses<br>- Both feet and hands are paralyzed<br>- Can not talk but can listen<br>- Can not go out of the house<br>- Move out of the house using knees, feet and hands<br>- When holds something, hands are weak. | - The indication started when 5 years old, since 1997 - 2007 (now)  | - Meal habit<br>- Cannot eat by self, always fed by family<br>- When defecate/ urinate always assisted by one family member<br>- Consume well water and rain water<br>- Adequate cleanliness<br>- Seven brothers and sisters<br>- 4 boys<br>- 3 girls<br>- Fifth kid in the family   |
| 7  | M.R             | Key                                    | F      | 57 years | - Suffers from malaria<br>- Suffering for 2 months<br>- Malaria attacks along with headache<br>- Malaria attacks in the night time   | - The indication started November 2006 up now   | - The causing factors are:<br>- Improper drinking water<br>- Drinking water is from well and rain water<br>- A lot of mosquitoes<br>Descendants:<br>- Seven children<br>a. 4 sons<br>b. 3 daughters<br>- Two deceased<br>a. 1 deceased son<br>b. 1 deceased daughter<br>Five survive |
| 8  | R.D             | Auyu/Bade                              | M      | 32 years | - Suffering from a kind of stroke  | - Suffering since 2003-2007   | - Have descendants<br>- 4 children   |

|    |   |                              |   |          |  |   |  |
|----|---|------------------------------|---|----------|--|---|--|
|    |   |                              |   |          | - Unclear vision<br>- Bad memory<br>- Painful from foot to hand<br>- Never come to hospital for a cure | (now)   | - 1 child deceased,<br>3 survive, 1 son and 1 daughter<br>- Consume well water everyday<br>- Often drink unboiled water  |
| 9  | J.I   | Serui / Bade                 | M | 23 years | - One of the feet became cramped and can not walk well   | - Indication started in September 2006-2007 (now)                                     | - Causing factor was football play.  |
| 10 | B.K   | Auyu/Bade                    | M | 4 years  | - Blood coughing   | - Suffering since 7 years old up to now   | - Causing factor was fallen from a tree when a child,  |
| 11 | S (An Amy)  | Bugis(Makassar)              | M | 50 years | - Cramp on both feet<br>Trembling left foot  | - suffered since 2004 (the last three years )<br>- Painful waist<br>- Troubled vision | - Bad sanitation<br>- Drinking water<br>- Troubled water<br>- A lot mosquitoes<br>- House is swamp area<br>- Main staple food is rice and tubers<br>5 descendants:<br>a. 1 son<br>b. 4 daughters   |
| 12 | S.K<br>Job: A student<br>Parents job: Civil Serpent (District office)<br>Mother's job:housewife | Auyu Bade                    | M | 2 years  | - Patient's complain:<br>- Puffy Right knee<br>- Not painful   | - Suffered since 2006   | - Water Consumption  |
| 13 | M(Farmer)   | Bugis (Sulawesi Selatan)     | F | 56 years | - Patient's complain<br>- Both feet are weak<br>- When walk, feet bones                                |   | - Drinking Water Consumption<br>- Drinking water is from well<br>- Womb goes down when working<br>- Head aches in the daylight.  |
| 14 | M.H   | Suku Auyu/Bade               | M | 43 years | - Patient's complain:<br>- Suffers from asthma   | - Suffered 1993-2007 (now)  | - Causing Factors<br>- He was active smoker before suffering this disease.<br>- Before the indication, he actively drank<br>- Consuming well and rain water<br>- Adequate sanitation<br>- Sleeping without mat/mattress<br>- House is made of wood |
| 15 | D.P   | Awı Tribe (Ogorito Village)  | F | 27 years | - Back bone, hand and feet are paralyzed   | - Suffering since six years ago (2000-now)  | - Can eat well<br>- Cannot work<br>- Cannot go out of the house<br>-Main Staples are sago and tubers<br>- Drink directly from well<br>- Drinking water is unboiled   |
| 16 | L.S   | Auyu Tribe (Ogorito Village) | F | 24 years | * Patient suffers from epilepsy<br>- Sometimes occurs unexpectedly<br>- It occurs for 3-4 hours        | - Suffered since six months ago   | - She cannot stand and walk from bed<br>Main staples are sago and tubers<br>- Drink well unboiled water  |
| 17 | A.M   | Auyu, (Osso Village)         | M | 52 years | - Both hands and feet can not move, cannot go out from house   | - Suffered Since seven years ago  | - House condition is unhealthy<br>- Both drinking water and bathing water is from well<br>- Drink well unboiled water<br>- A lot of mosquitoes<br>- Water condition in Wosso is good enough  |
| 18 | T.S   | Auyu, (Asset Village)        | M | 47 years | - Both lower parts of feet and hands are cramped   | *Suffered since 1 month ago   | - He cannot go out of the house because of the   |

|    |              |                         |   |          |  |  |   |
|----|--------------|-------------------------|---|----------|--|--|---|
|    |              |                         |   |          | - The indication started in December 2006<br>- Defecate and urinate  |  | sickness<br>- Cannot do hard daughters and 3 sons<br>- All children alive<br>- The first kid goes to one of the university in Menado                    |
| 19 | H.A(Farmer)  | Auyu,(Homlikya Village) | M | 54 years | - Back bones, both feet and hands are paralyzed<br>- Cannot walk<br>- Defecate and urinate always assisted by family | - Indication has started since 2006 to date. | - The main meal is grilled sago<br>- Nutrition is not given well attention<br>- Both drinking water and sanitation is from well<br>- Water is not plain |
| 20 | P.Y          | Auyu(Homlikya Village)  | M | 48 years | - Paralyzed Both feet and hands are Paralyzed<br>- Can hardly talk   | - Has suffered for 2 years                   | - Married, 7 descendants, 5 sons, 2 daughters   |
| 21 | A.Y          | Auyu(Homlikya Village)  | F | 70 years | - Cramped hands and feet<br>- Can walk but can hardly work   | - Suffered since 2000                        | - Descendants: 9 children, 2 sons, 7 daughters<br>- Deceased husband<br>- Consume unboiled well water   |
| 22 | S.S          | Awiyo(Homlikya Village) | F | 16 years | - Suffering from abscess<br>- Puffy on foot tarsus   | - Suffered since 5 years ago                 | - Married<br>- One son  |
| 23 | T.Y          | Auyu                    | F | 54 years | - Left foot paralyzed  |  | - Has four children, 3 sons 1 daughter  |
| 24 | Z.E (Farmer) | Bugis(Makassar)         | M | 87 years | - Paralyzed on the left foot.<br>- Traditionally treated<br>- Once fell from height                                  | - Suffered since March-April 2006            | - 2 descendants, 1 son daughter<br>- Consume water from sago tree bank  |
| 25 | K.K          | Auyu                    | M | 54 years | - Cannot talk<br>- Both feet and hands are paralyzed<br>- Cannot go out of the house<br>- Can eat<br>- Usual meal    | - Since 2003                                 | - 4 children, 3 sons, 1 daughter<br>- Drinking well water<br>- Bathing with " hot water   |
| 26 | S.T          | Key                     | M | 46 Years | - Indicators:<br>- Left hand is cramp  | - Suffered since three years ago             | - Drink well water<br>- Being treated traditionally<br>- Descendants: 3 children, 1 son 2 daughters   |

• **Specific (Osso Village Cases)**

- There were 5 patients in Osso village. One 60-year-old patient started to get sick when she was thinking about her dead husband and dead 4 children. Her suffering parts of body were thigh bones, feet, weak nerves, skinny body and weak brain. Four other patients suffered from rheumatism on their feet and hands as a result of cold weather, hard working and submerging.
- Less consuming healthy/nutritious food.
- Teeth sickness as a result of improper feeding and consuming unboiled water.

**REFERENCE**

1) Gajdusek DC, Salazar AM. Amyotrophic lateral sclerosis and parkinsonian syndromes in high incidence among the Auyu and Jakai people of West New Guinea. Neurology 1982; 32:107-126.